

Age Related Transitions:

Older Parents Caring for Adult Sons/Daughters with Lifelong Disabilities

Funded by NHRDP/CIHR



**Age Related Transitions: Older
Parents Caring for
Adult Sons/Daughters with
Lifelong Disabilities**

Final Report - February 2002

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The Investigators

EXECUTIVE SUMMARY

There are growing numbers of older parents caring for adult sons/daughters with lifelong disabilities. They experience changes in their caregiving needs, routines, and patterns as both the caregivers and care receivers grow older. These families often find themselves facing increasing demands while experiencing diminishing resources of health, income and social support. *Older Parents Caring for Adult Sons/Daughters with Lifelong Disabilities* is a collaborative research project undertaken to inform the development of policy and programs affecting families in Atlantic Canada where older parents, aged 65+, are caring for adult sons/daughters with lifelong disabilities. Specifically, this work enhances our understanding of the scope of the issue, enhances our knowledge of how the caregiving relationships in these families are affected by the aging of both parents and adult sons/daughters with lifelong disabilities and enhances our understanding of how the formal sector, through policy and programs, can support aging families over the next decade, particularly in reference to future planning for the care of sons/daughters with lifelong disabilities. Qualitative and quantitative methods were used to gather relevant information.

A literature review was conducted to explore issues and identify gaps pertaining to aging parents caring for their adult sons/daughters with lifelong disabilities, focussing on the experiences of parents and their changing needs as they age. These parents are dealing with their own age-related changes such as decreased energy levels, and increased chronic illness as well as responding to the changing age-related needs of their sons/daughters. In addition, they must plan for their son's/daughter's future care when they can no longer fulfill their caregiving role. The research indicates future planning can be a difficult and emotionally trying process compounded by the lack of services and suitable options, restrictive policy eligibility, previous experiences with the service delivery system, perceptions of formal support, and family dynamics arising from caring for sons/daughters with lifelong disabilities. The full literature review (57 pages), complete with citations and references, is available on request.

To gain a clear understanding of the scope of older parents caring for adult sons/daughters with lifelong disabilities, a secondary analysis was conducted using the 1996 Canadian General Social Survey (quantitative component). The analysis addressed: the prevalence of this caregiving situation; demographics of the parents and the sons/daughters with lifelong disabilities; parents' health status; the types and amounts of care parents are providing to their sons/daughters; families' unmet needs; and the impact of caregiving on the parents. The findings revealed there are approximately 20,000 parents aged 65 or more, caring for adult sons/daughters with long-term health problems. Following this group are 40,000 parent caregivers in the age group 45-64. Until this analysis, very little was known about these caregivers of adult sons/daughters. Among the older parents, many are widowed and some are themselves in need of help. Older parent caregivers identify financial and respite issues as unmet needs. Yet, despite the apparent challenges, these older parents report predominantly positive feelings associated with their roles as caregivers.

Understanding the everyday experiences and needs for support for older parents caring for their children involved 56 in-depth interviews with parents from the four Atlantic provinces (qualitative

component). Collaboration with provincial agencies/organizations involved with families caring for the disabled helped to identify voluntary participants with a diversity of experiences. Parents were interviewed using a semi-structured format exploring their experiences and needs for support. The interviews were taped and transcribed for analysis. Embedded within the stories of parents caring for adult sons/daughters with lifelong disabilities was evidence of broader societal ideologies of family, age, and disability. Key themes related to age related transitions and perspectives in parent-child relations were displayed through analysis, specifically: reciprocity; centrality of the family; different paradigms for families and systems; uniqueness of families; family practices and processes; coping strategies; mitigating factors; small social networks; different issues in care of adults with developmental disabilities and psychiatric illness; health and social age-related transitions; barriers to future planning; inequities in funding arrangements; and challenges in relationships.

One of the primary goals of this research project, endorsed by parents in the interviews, was to inform and guide policy decisions by identify and exposing some key issues facing older parents caring for sons/daughters with lifelong disabilities. To this end, parents, policy makers, civil servants and representatives from agencies/organizations that support these caregivers were invited to public forums in their home province to hear and discuss the research findings. The forums consisted of a presentation of the research findings, followed by round table discussions by forum participants. These discussions were to serve as a ‘litmus test’ of the validity of the research findings and to offer further dissemination strategies.

Recommendations emerging from this study reflected all the components of the research endeavour to assist older parents caring for sons/daughters with lifelong disabilities. It is recommended that:

- 1 (a). All levels of government use a **family lens** to frame public policy.
- 1 (b). Publicly funded services be expected to use a family lens in delivery of services.
2. Flexibility be incorporated as a key value underlying policy development, interpretation and implementation.
3. Funding policies be reviewed with the intent of increasing flexibility and minimizing inequities.
4. Policies be reviewed with a view to determine their applicability and flexibility to respond to changing family needs as both caregiving parents and adults with lifelong disabilities age.
5. Service providers initiate family-focussed services that support the aging family unit and respond to their changing needs.
6. Curricula for service providers who serve this population in the aging and disability sectors be reviewed to ensure course content includes material relevant to aging with a lifelong disability.
7. Assistance in future planning be appropriately funded as a recognized service.
8. Retirement options for older persons with lifelong disabilities be an area for program development.
9. Curricula for health care providers include both expected and potential health issues for persons aging with lifelong disability.
10. A navigator position be created within each province to support families seeking information and services from the formal system.

*Age Related Transitions: Older Parents Caring for Adult Sons/Daughters
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1. INTRODUCTION

1.1 Background

Caregiving needs, routines, and patterns change for elderly parents caring for adult sons/daughters with disabilities as both the caregivers and care receivers grow older. These families often find themselves facing increasing demands while experiencing diminishing resources. Aging can also trigger the need to access alternate care arrangements. The purpose of the research study entitled “**Older Parents Caring for Adult Sons/Daughters with Lifelong Disabilities: Age-Related Transitions**” was to explore the ways in which caregiving provided by parents to adult sons/daughters with disabilities changes as both groups age and to identify the types of formal support that would be most useful for these aging families as they face inevitable transitions.

This project addressed the theme of Determinants of Population Health as identified in the 1998 NHRDP competition. The research contributes to the knowledge base for national and regional policy development and planning by enhancing our understanding of the needs of the identified group; and, it offers an opportunity to be proactive rather than reactive to future needs. The project objective was to enhance our understanding of the interactions and relative importance of such health determinants as social support networks, coping skills, gender and culture as they relate to the circumstances faced by these families.

The study was designed to yield information about this growing group of families and their needs, enriching the knowledge available, to inform policy and program development over the next decade. By examining parents’ responses in the 1996 General Social Survey (quantitative component) and through in-depth interviews with parents caring for adult sons/daughters with lifelong development disabilities (qualitative component) in four Atlantic provinces, contextual information about these families and their need for support emerged.

Part of the dissemination process was to present the key themes, emerging from the research, at four public forums in each of the Atlantic provinces with the intent of gaining feedback to their relevancy, discuss strategies for future dissemination of the research findings and strategies to ensure parents’ voices were being heard. These discussions helped to frame the recommendations emerging from the study. This in-depth knowledge of the transitions these families face as they age will benefit policy makers, service providers, recipients of services and planners in both the aging and disability sectors over the next decade.

1.1.1 Partnerships and Collaboration

Co-Principal Investigator Deborah Norris, PhD., Department of Family Studies and Gerontology, Mount Saint Vincent University. Dr. Norris is an Associate Professor in Family Studies and the

Chairperson of the Department of Family Studies and Gerontology. Her responsibilities for the project included writing the proposal, conducting interviews, qualitative analysis, presentations and reports, forum facilitator and project monitoring.

Co-Principal Investigator Marlene MacLellan, MAHE, Nova Scotia Centre on Aging, Mount Saint Vincent University. Ms. MacLellan is the Associate Director of the Nova Scotia Centre on Aging and part time faculty in the Department of Family Studies and Gerontology, Mount Saint Vincent University. Her project responsibilities included writing the proposal, conducting interviews, qualitative analysis, presentations and reports, forum facilitator and project monitoring.

Co-Investigator Dr. Gordon Flowerdew, Community Health and Epidemiology, Dalhousie University. Dr. Flowerdew is an Associate Professor in the Department of Community Health and Epidemiology, Dalhousie University and advised and assisted in all aspects of the quantitative analysis of the 1996 General Social Survey data.

Co-Investigator Dr. Kathleen MacPherson, Department of Community Health and Epidemiology, Dalhousie University. Dr. MacPherson is an Assistant Professor in the Department of Community Health and Epidemiology, Dalhousie University and was responsible for assisting in the quantitative analysis and presentation of the analysis of the 1996 General Social Survey data.

Collaborators The collaborators in this report are the four provincial bodies in Atlantic Canada which link the disability community and the policy and programs branch of government. These bodies are **Disabled Persons Commission in Nova Scotia**, the **Premier's Council on the Status of Disabled Persons in New Brunswick**, **Prince Edward Island Council of the Disabled Inc.**, and **Coalition of Persons with Disabilities in Newfoundland**.

Role of collaborators The collaborators participated in this project in full recognition of the need to address the concerns of these families. The participation of these groups was critical to carrying out the purpose of the project because they have specific interests and mandates in policy development and program planning. They have observed the aging of their constituents over the years and they recognize that the next decade will signal major changes for many families.

These groups were a sounding board to ensure the data gathered in the research process were relevant to current policy concerns, and were presented in a useful format for policy makers and practitioners, thus contributing in a meaningful way to the body of knowledge in this area. Their expertise was a significant resource in several phases of the project implementation. They assisted in the identification of participants and those who need to receive project materials; they had input into the information needed to inform policy and program development; and they played a key role in the dissemination of information, specifically, in co-sponsoring a provincial public forum for decision-makers, program planners, service providers and families.

1.1.2 Assumptions

The process of aging encompasses a number of critical transition points that affect the caregiving relationship between parents and their adult offspring with disabilities. The literature (Janicki, Bishop, Force, Grant-Griffin, Hacker, Lawrance, LePore, Lucchino, McCallion, & Schwartz, 1996; Jennings, J., 1987), anecdotes from families, and observations from professionals, support the assumption that caregiving arrangements which have been in place for many years undergo substantive change as both caregivers and care receivers age. There is a great need to assist families with the inevitable task of planning for a time when the current arrangements are no longer viable. Therefore, this research considered how the caregiving changes as parents and adult sons/daughters with disabilities age, rather than ‘does it change?’ in order to support parents in their transition.

It is well understood that caregiving is primarily “women’s work” (Walker, Pratt & Eddy, 1995). Therefore, in this research an interaction between social support, family caregiving and the determinants of gender and culture is assumed; it is not possible to consider caregiving without being conscious of the interconnectedness of these factors. As well, coping skills are an important factor in a person’s ability to adapt to changing circumstances. Study of the effect of change on individuals and groups needs to consider their coping skills.

The researchers use the broad term “disabilities”, encompassing a wide range of conditions involving various degrees of mental and physical impairment, rather than specific diagnostic labels for a number of reasons. First, in the quantitative component of the study, it was not possible to gather information from the GSS dataset on the specific types of disabilities. Second, it is evident from the earlier work with older parents in the *Preparing for Change* focus groups that their efforts centered on the level of care needs, not the type of disability. However, it is likely that parents will be more involved in future care planning for an adult son/daughter when an intellectual disability is present. To further understand this perspective, the qualitative component of the study focussed on a subset of parents who are caring for adult offspring with developmental disabilities such as Down Syndrome, intellectual disability, autism or cerebral palsy. This subset also included a smaller group of parents caring for sons/daughters with of psychiatric disabilities. Janicki et al. (1996, p. 63) indicated the current view by service providers is that: “Diagnosis is a system issue - not a family issue.”

Developmental disability is defined as “a severe, chronic disability...” (Accardo, Whitman, Laszewski, Haake, & Morrow, 1996, p. 87) manifested during a developmental period, from birth to age 22. It is defined functionally as resulting in substantial limitations in “three or more areas of major life activity: 1) self-care; 2) receptive and expressive language; 3) learning; 4) mobility; 5) self-direction; 6) capacity for independent living; and 7) economic self-sufficiency...” (Accardo et al., 1996, p. 87).

1.1.3 Foundation Work.

In 1996 -1997, the Nova Scotia Centre on Aging, Mount Saint Vincent University, received funding from New Horizons - Partners in Aging, Health Canada, for the project *Preparing for Change* (MacLellan & Cosway, 1997). This project addressed the issue of future planning for the care needs of adults with disabilities when the current caregiving arrangements were no longer viable. The primary purpose was to develop an educational package for elderly parents to encourage them to make concrete plans. The package was intended for use by families and service providers to stimulate discussion, identify issues and share experiences and was based on the views of parents themselves.

This national project was coordinated by the Nova Scotia Centre on Aging, in collaboration with the Queen Elizabeth II Health Sciences Centre in Halifax, NS, and the Canadian Gerontological Nursing Association. The parents' input was gathered using the technique of focus groups. The focus groups were semi-structured and were intended to inform the development of the handbook and production of the video. A total of fifty-five parents met in six Canadian cities; one focus group, consisting of eight professionals, met in Halifax; and there were thirty-one key informants across Canada. In addition, sixty people from the six cities received training as peer resource persons to share the educational package.

It was clear at the completion of *Preparing for Change* that many issues identified during the focus group discussions required further exploration beyond the scope of the original project, particularly issues relevant to age-related transitions in caregiving. Parents were unanimous in the recognition that their own aging and the aging of their sons/daughters brought new challenges to the caregiving role. They referred to the reciprocity in the relationship. Many believed that it was important to foster independence while they (the parents) were still able to help with changes. The overwhelming message received from parents was that they were "tired" and would welcome some support both in meeting the day-to-day needs and in planning for future care. They talked about the difficulties and struggles in accessing and obtaining services for themselves and their sons/daughters. They made it very clear that they wanted to be involved in the planning for future care, seeing it as their role, but they need opportunities and assistance to do so. Based on *Preparing for Change*, the current project furthers the understanding of what changes occur in the caregiving relationship as both parents and adult offspring with disabilities age, and what formal supports are required to respond to changing needs.

1.1.4 Rationale

Increased life expectancies of both the parents and adult sons/daughters with lifelong disabilities along with the changes that accompany the aging process, deinstitutionalisation policies, a focus on community based care, and changes in family configurations are some of the factors that have coalesced in the past decade to create new challenges to both families and society (Smith, Tobin & Fullmer, 1995). The reality is that there are growing numbers of aging caregiving families who are facing increasing challenges while coping with diminishing resources of health, income and social support.

The assistance provided to adults with developmental disabilities and chronic mental illness by their immediate families, especially their parents, is a cornerstone of the social support system for that population. Ninety-eight per cent (98%) of the population with disabilities between the ages of 15-64 lives in the community and eighty per cent (80%) of this group lives within families (Statistics Canada, 1995). The 1991 Health and Activity Limitation Survey indicates that eleven per cent (11%) of persons with disabilities aged 15-64 are in the family status category of “child”. Existing information does not easily lend itself to determining the numbers of families where there are aging parents caring for adult sons/daughters. Existing national databases such as the 1996 General Social Survey are potential sources of information in determining the scope of the issue.

The literature strongly suggests that the future care of sons/daughters with disabilities is a major concern to caregiving parents, despite the fact that planning is often delayed until a crisis arises (Smith & Tobin, 1993). Parents clearly want to ‘look after their own’, but as they age and their sons and daughters age, the care that is needed and what care they are able to provide may change. Parents may require different levels of support from the formal sector than they required in the past. Future care is also a societal issue: “Future planning for the community-based aging population with disabilities is a critical social need” (Lefley, 1997, p. 448).

In the next decade, there will be a need for effective policy and program development to support the changing needs of families. To be effective, policy and programs must recognize and build on the strengths of the informal and formal sectors and allow the emergence of collaborative efforts that support the broad notion of healthy living for both caregivers and care receivers. A federal report, *Equal Citizenship for Canadians with Disabilities: The will to act* (Federal Task Force on Disability Issues, 1996), suggested the need for development of a disability policy framework that could cut across organizational lines and be more comprehensive than what is currently available. If the government acts on the Task Force report, considerable information will be needed to inform the process.

1.2 Research Goals and Objectives

1.2.1 Research Goals

The goal of the project was to inform the development of policy and programs which affect families in Atlantic Canada where there is an elderly parent(s), aged 65+, caring for an adult son/daughter with lifelong disabilities. Specifically, this work: 1) enhances our knowledge of how the caregiving relationship in these families is affected by the aging of both parents and adult sons/daughters with disabilities and, 2) enhances our understanding of how the formal sector, through policy and programs, can support aging family units over the next decade, particularly in reference to future planning for the care of sons/daughters with disabilities.

1.2.2 Research Objectives

In regard to families where there are parents aged 65 and over, providing care for adult

sons/daughters with lifelong disabilities, the research objectives were to:

1. Provide a summary of Canadian data from the 1996 General Social Survey on:
 - a) Prevalence of this caregiving situation
 - b) Demographics of the parents and the sons/daughters with lifelong disabilities
 - c) Health status of parents
 - d) Types and amounts of care
 - e) Unmet needs
 - f) Impact of caregiving on the parents.
2. Identify age-related transitions in caregiving relationships.
3. Display and interpret concrete practices characterizing the daily lives of aging parents caring for adult sons/daughters with developmental disabilities (also aging) and the meanings underpinning these practices by conducting interviews with families.
4. Identify issues relevant to the formulation of social policy.
5. Identify the types of formal support that would be most useful in meeting the day-to-day needs and in planning for future care needs.
6. Foster links between the aging and disability sectors to strengthen the response to family needs.

1.3 Outline of Report

The following report was prepared for NHRDP, the funder and CIHR, service providers and families caring for adult sons/daughters with lifelong disabilities. Section 1 has provided the rationale and background of the project, the research goals and objectives and introduced the researchers and collaborators. An executive summary of the literature review exploring current research findings related to older parents caring for adult sons/daughters with lifelong disabilities is presented in Section 2. The complete literature review and bibliography (57 pages) is available on request. Section 3 examines the scope of the issue, the quantitative research component, by conducting a statistical analysis on the data obtained from the 1996 Canadian General Social Survey.

The qualitative research component, Section 4, presents the everyday experiences of families caring for their sons/daughters with disabilities. Parents voices are displayed, organized by themes emerging from the interviews using both age related transitions and parent-child relationships perspectives. This section concludes with a summary of services parents suggested that would assist them in caregiving and future planning.

The research findings were presented at four public forums in each of the Atlantic provinces. The structure and organizations of the forms, attendance and forum discussion is presented in Section 5. Implications, recommendations and conclusions arising from this research process are summarized in Section 6. Section 7 details the dissemination strategies used to disseminate the research findings. The complete bibliography is presented in Section 8 followed by the Appendices in Section 9.

2. LITERATURE REVIEW

An in-depth literature review exploring issues related to older parents caring for adult sons/daughters with lifelong disabilities was conducted. The full literature review (57 pages), complete with citations and references, is available on request. The following introduction (section 2.1) has been taken from the full report and addresses the scope and focus of the review, and a definitions of terms used in the review. The executive summary of the literature that follows (section 2.2) is a condensed version of the major themes emerging from the literature review.

2.1 Introduction to the Literature Review

This review examines the literature pertaining to aging parents who are the primary caregivers to their adult sons/daughters with lifelong disabilities, focussing on the experiences of parents and their changing needs as they age. Literature searches were conducted using several databases available through Ebsco Academic Search Elite, including Academic Search Elite, PsychINFO, Sociological Abstracts, ERIC, Ebsco Online Citation, as well as Medline and Ageline. Further searches were conducted at the Mount Saint Vincent University Library and in the specialized collection at Caregiver Resource Library at the Nova Scotia Centre on Aging, Mount Saint Vincent University. Keywords used singly and in combination included: caregiving; disabled persons; mental retardation; developmental disabilities; intellectual disabilities; resiliency; reciprocity; social support; adult offspring; mental disorders; mental illness; deinstitutionalization; planning.

In the context of this literature review, the terms *mental retardation*, *developmental disabilities*, *psychiatric disorders* and *mental illness* are subsumed under the broad category of *disabilities*. For purposes of clarity or comparison, or where direct quotes from original sources are used, specific disabilities may be named. The authors considered in this paper typically use either mental retardation or developmental disabilities to describe conditions that result in various levels of cognitive and physical impairment. The former term is used most often in literature originating in the United States, whereas developmental disabilities and more recently, intellectual disabilities, are the most commonly used terms in Canada. For the purposes of this review, the term *intellectual disabilities* refers to a range of conditions that results in significant impairment, is acquired before the age of 22, and will continue indefinitely (Salvatori, Tremblay, Sandys & Maraccio, 1998).

None of the authors reviewed in this paper define mental illness per se, but list the specific diagnoses of the offspring of the participants in their research, the majority of whom have been diagnosed with schizophrenia. This broad category of psychiatric disorders is referred to as *mental illness*. Consistent with current standards, the terminology used herein puts people before the disability, e.g., - adult with intellectual disabilities rather than an intellectually disabled adult.

This literature review focuses on parents' experiences caring for adult offspring with lifelong disabilities, and therefore the issues raised are considered vis-`a-vis parents' perspectives and based

on the assumption that caregiving parents have been vested with the ultimate decision-making responsibilities for offspring with disabilities. While it is recognized that the assumption that parents should make choices for offspring with disabilities has been challenged and debated, and supportive decision-making models for persons with disabilities exist, issues surrounding the right of offspring with disabilities to self-determination are beyond the scope of this paper.

2.2 Executive Summary of Literature Review

2.2.1 Older Parents Caring for Adult Sons/Daughters with Lifelong Disabilities

Out of either choice or necessity, the majority of adults with lifelong disabilities live at home with their families. Older parents caring for adult offspring with intellectual disabilities or mental illness are a unique group of family caregivers in that they are among the first to have experienced a prolonged caregiving role of this nature. Prior to the current cohort, few people with lifelong disabilities lived into adulthood and were more likely to live in an institutional setting. Now most individuals with mild to moderate intellectual disabilities, with the exception of people with Down syndrome, will experience life expectancies similar to the general population and will live in a community setting.

The current cohort of older parents raised their sons/daughters during a period in which segregation and institutionalization of individuals with disabilities was the norm. Few if any services were available to families who chose not to institutionalize their offspring. Even after the advent of community-based services, few older parents utilized them, relying on their own resources even when their needs change. In addition to having to deal with their own age-related changes such as decreased energy levels, sensory loss and increased susceptibility to chronic disease or illness, they must respond to the changing age-related needs of their sons/daughters. As well, they must plan for their future care. Developing a permanency plan to address the residential, legal and financial issues, that can be activated when parents can no longer fulfill their caregiving role, can be a difficult and emotionally trying process.

There is limited information available on aging with a lifelong disability, however, with increased life expectancy for most persons with lifelong disability, information is being gathered as this current cohort moves into older age. There is no consensus as to the chronological age at which a person with lifelong disabilities is considered “aged.” As well there is great heterogeneity among individuals with lifelong disabilities, and while some conditions associated with disabilities exacerbate the aging process, others cause no deleterious effects. The paucity of data on this segment of the population impairs policy development, program planning and service provision. This will become increasingly significant, as an overall aging trend in the North American population is increasing the ratio of older to younger caregiving parents, and will continue to do so in the coming decades. Early indications suggest the social service sector will be unable to respond to the needs of this segment of the population.

What is known however, is that as adults with disabilities and their parents age, their needs change. Older parents caring for adult sons/daughters with lifelong disabilities face different challenges and have different needs than younger parents in this situation. Whereas younger families require support in the areas of education, socialization and vocational training, older families' needs are related to health care, long term care and retirement. A great, but least met, need of older parents is in the area of future planning.

2.2.2 Future Planning

A substantial number of aging parents who are caregivers to their adults sons/daughters have not made adequate plans for the transfer of care. While this may be surprising given that the future care of their sons/daughters with disabilities is a pervasive worry of most parents, there are many factors that can deter planning. Some of the many reasons why parents postpone developing permanency plans include: the lack of suitable options; the assumption other family members will take over the task; the assumption their offspring with disabilities will predecease them; the lack of services to assist in permanency planning; the gratification derived from their caregiving role; and the support and assistance received from their offspring with disabilities that enable these aging parents to maintain their independence.

Research suggests that formal service use encourages higher stages of future planning (Smith, Tobin & Fullmer, 1995a), however older parents caring for adult sons/daughters with disabilities use few, if any, services. Impediments to service use may exist at many levels: parents may not feel the need for services if they perceive they can meet their offspring's needs; increasing frailty of older parents may make accessing services difficult; parents' previous experiences with the service delivery system may have left them mistrustful and fearful that any involvement with the system will lead to their offspring's removal from the home; attitudes such as ageism may hinder parents' use of service; the dearth of services available during their offspring's younger years resulted in parents adapting and coping without formal supports and, having done so most of their lives, they may not see a need to access services in their later years.

A critical task for service providers is to address this double bind situation - older parents perceive a need for services to assist them in future planning, and service use facilitates permanency planning, yet older parents are less likely to use these services. Outreach efforts to increase overall service use and employment of other mediums to disseminate future planning information such as informal workshops, self-help books and videos may address this issue. As well, support groups may serve as a bridge between formal social services and parents.

2.2.3 Caregiver Experiences

Whereas little is known about the changing needs of older parents caring for adult sons/daughters with lifelong disabilities, research does offer information regarding their caregiving experiences. The majority of research focuses on the perceived psychological, social and economic costs of caregiving. Higher stress levels in caregivers are related to higher levels of intellectual disabilities, physical

limitation and the frequency of maladaptive behaviours (Hayden & Goldman, 1996; Heller, 1993). The greater the perceived need for supervision of the adult with disabilities, the greater the caregiver stress (Hayden & Goldman, 1996). While caregiving can be a stressful and burdensome experience, the level of perceived burden experienced by parents caring for adult offspring with intellectual disabilities may not be markedly higher than other caregivers (Smeltzer et al., 1996).

The situation is somewhat different for parents caring for adult sons/daughters with mental illness. Mothers of adult offspring with mental illness report poorer relationships, more burden, fewer informal supports and more depressive symptoms than mothers of adult offspring with intellectual disabilities (Greenberg et al., 1997; Pruchno et al., 1996a; Greenberg, Seltzer et al., 1993). The differences in the caregiving experience can be attributed to difference in the caregiving context, such as the late onset and unpredictable course of mental illness, etiological attributions and the stigma attached to mental illness (Greenberg, Seltzer, Krauss & Kim, 1997; Pruchno et al., 1996a).

Findings on the impact of age on burden have yielded mixed results. Some researchers report less burden among older parents of adults with lifelong disabilities (Hayden & Heller, 1997; Seltzer et al., 1996), others report no difference in the level of burden between younger and older parents caring for offspring with disabilities (McDermott et al 1996). Other studies have found the perception of negative age-related changes to be associated with burden in older mothers of adults with intellectual disabilities (Smith, Tobin & Fullmer, 1995a). Age does seem to affect the content of burden, however. Whereas younger parents of offspring with severe mental illness report more burden related to family conflict, older parents are more burdened by issues related to the ongoing and future care of their offspring.

Parents caring for offspring with lifelong disabilities experience gratifications as well, although few studies have examined the positive aspects of caregiving. Years of experience in providing care to their offspring contribute to the coping skills of these parents. Research has found these caregiving mothers to be resilient, optimistic and healthier than non-caregiving peers (Seltzer et al., 1996). Parents coped and thrived in their caregiving role over time and report receiving benefits from it. Caregiving reciprocity is an important factor in predicting the well-being of both parents and adult offspring with lifelong disabilities. While the exchanges are not quid pro quo, parents report receiving significant benefits from the caregiving relationship such as instrumental assistance, financial contributions and expressive support (Greenberg, 1995; Greenberg et al., 1994; Kropf, 1997). Being a caregiver to an adult son/daughter may confer a sense of purpose and usefulness and parents in this position may gain an identity and meaning from their role that is different from other parents.

2.2.4 Siblings

The specific diagnosis influences the nature of the relationship between adults with lifelong disabilities and their non-disabled siblings. Siblings of adults with intellectual disabilities perceive their brothers/sisters to have had a positive effect on their lives. Siblings of adults with mental illness report being less affected by their sibling's illness, but of those who did report an impact, half rated the experience as being mostly negative (Seltzer, Greenberg, Krauss, Gordon & Judge, 1997).

However, regardless of the diagnosis, siblings maintain a consistent pattern of involvement throughout their lives and the literature suggests the majority of siblings expect to assume some caregiving responsibilities for their brothers/sisters with disabilities when parents are no longer able to fulfill this role.

While most siblings were willing to accept caregiving duties at a future date, some parents are reticent to have siblings assume responsibility for their brothers/sisters with lifelong disabilities because they fear disruption of non-disabled offspring's lives or that the burden will be too great.

2.2.5 Culture

One aspect of the caregiving experience is largely overlooked, and that is the impact of culture. Minority group members who care for adult offspring with lifelong disabilities experience more stress, have less access to services, are poorer and are more likely to have had disappointing experiences with social service agencies than majority populations. It is important to note that extracting ethnic and cultural variables from socioeconomic factors is difficult.

2.2.6 Services, Programs, Policies and a Research Agenda

Neither the aging nor intellectual disability service systems have been fully responsive to the needs of older parents caring for adult sons/daughters with lifelong disabilities. While the changes in service provisions and social policy in the past several decades are viewed as positive, discriminatory societal attitudes, inadequate government funding and limited accessibility to individual services persist. Despite the introduction of community-based services and government directives on integration and inclusion, there are too few resources to meet existing needs; restrictive eligibility criteria in terms of age, type and level of disability; lack of funding; and lengthy waiting lists for residential services. There are few cross-trained personnel as there has been little need in the past for the intellectual disability sector and the aging sector to merge. As well, there is a paucity of services to support employment, retirement and leisure activities for older adults with lifelong disabilities.

In order for the service delivery system to become more meaningful and responsive to the needs of older families, policies must change. Adopting a *family as client* focus as opposed to the *individual as client* would acknowledge that parents are more than just resources but also clients with needs of their own. As families are the primary purveyors of care and support for individuals with lifelong disabilities, it is essential they be supported in this role.

Individualized funding approaches, which provide direct funding to families to purchase the supports they determine they need, have been instituted in some areas of Canada. This represents a significant change in program delivery as previously the majority of funding for services for individuals with intellectual disabilities has gone to institutions.

The lack of cooperation among service delivery systems is an obstacle to service delivery. Collaborative efforts on the part of the fields of gerontology, rehabilitation and intellectual disabilities to develop an interdisciplinary approach are necessary to address the needs of older parents and their adult sons/daughters with lifelong disabilities. As well, policies should encourage collaboration of the various levels and departments within the government to reduce service duplication, address disjointed service delivery and ensure needs are met.

Areas that would benefit from further study include: systemic and cultural barriers to service use; barriers to future planning; the changing needs of family caregivers over the life course; the intersection of family, aging and disabilities and its implications; the intersection of aging and disability and its implications; and an analysis of the ideologies such as gender, aging and ability that are present in the everyday life of older parents caring for adult sons/daughters with lifelong disabilities.

The literature review identified key issues affecting older parents caring for sons/daughters with lifelong disabilities while highlighting the need for further research. Section 3 addresses the prevalence of older Canadian families caring for sons/daughters with lifelong disabilities, the range of care they provide and the impact this caregiving has on the family.

3. SCOPE OF THE ISSUE: QUANTITATIVE COMPONENT

3.1. Data Collection

The quantitative component involves secondary analysis of an existing database, the 1996 Canadian General Social Survey (GSS), Cycle 11: Social and Community Support (Catalogue # 12MOO11 GPE, Statistics Canada). This source of data was chosen after consideration of several alternatives, such as the Health and Activity Limitation Survey (HALS). Strengths of the GSS include: population-based sampling methods; Canada-wide sampling (though not including the Territories or individuals living in institutions); demographic information on both the caregiving parent and their adult son/daughter with long-term health or physical limitations; detailed information regarding care provided, both formal and informal; and respondents' assessments of unmet needs and of the impact of caregiving on their personal lives.

The GSS involved making phone contact with randomly selected households and using a computer algorithm to randomly select a "respondent" from all the members of the household who were aged 15+ years. If the respondent could not be interviewed due to health reasons, a proxy could be interviewed. A total of 12,756 respondents were interviewed, including 3,546 aged 65-74, 1,925 aged 75-84, and 481 aged 85+. These numbers represent "oversampling" of the older population; the GSS sampled different groups with different sampling probabilities or intensities. Therefore, estimates derived from the GSS must be weighted accordingly to reflect the Canadian population.

The caregivers analyzed in this study are a subset of GSS respondents, namely those who are parents aged 65+ caring for adult sons/daughters with "Long-term health or physical limitations (Any condition lasting or expected to last more than six months and which can be either chronic or permanent.)" (GSS Cycle 11 Questionnaire Package, 1998:2). The variables examined fall into four main categories: demographics, types and amounts of care, unmet needs, and impact of caregiving.

Demographic variables. These include caregiver (parent) age (available by 5 year groups), sex, marital status, household composition, and urban/rural residence. There is also detailed "roster" information on every person receiving care from this parent, including the adult son/daughter with long-term health problems.

Types of Care. There is detailed information available on practical, day-to-day care activities such as meal preparation, house cleaning, house maintenance, grocery shopping, transportation, banking/bill paying, bathing, toileting, toenail care, brushing teeth, shampooing, dressing, as well as general checking in on the care recipient, and provision of emotional support. The database also contains information about care provided to the parent, and from whom.

Unmet Needs. The parents are asked about their own ability to manage each of the activities listed above (meal preparation, etc.) and whether the assistance they receive from others is adequate. They are asked what changes they would make in each activity to meet their needs.

Impacts of Caregiving. The survey captures the various impacts of caregiving on the parents who provide care, including changes in their social activities, holiday plans, living arrangements, paid employment, or health.

3.2 Analytic Methods

The data were accessed through the Data Liberation Initiative, according to the agreements signed by both Mount Saint Vincent University and Dalhousie University. Statistical analyses were conducted using the SAS statistical package. Analytic methods for weighting and handling the complex sampling design followed the recommendations in the GSS Microdata File Documentation and User's Guide (Catalogue#12MOO11GPE, Statistics Canada); where applicable, this meant using the weighting factor provided. However, unweighted data only are displayed where the number of respondents contributing to the estimate was small (< 15), or where the coefficient of variation was high (> 3.3). This quantitative component addressed research objectives 1 and 2 (Section 1.2.2).

Objective 1a (Prevalence). The number of cases of older parents caring for adult sons/daughters with disabilities was estimated by selecting respondents aged 65+ and subsetting those who provide help to their adult son/daughter due to his/her long-term health or physical limitation. The sum of the weights in the subset is an estimate of the number of Canadians aged 65+ in the 10 provinces who care for adult sons/daughters with disabilities. The prevalence of this caregiving situation was obtained by dividing by the overall number of Canadians aged 65+. To help place these estimates in context, additional prevalence estimates are provided for older Canadians caring for spouses or others with long-term health problems (but who are not caring for adult sons/daughters), as well as for older Canadians who do not care for anyone with long-term health problems.

Objectives 1b through 1f (Demographics. Types of care. Unmet needs and Impact of caregiving). Simple frequency counts, cross tabulations and descriptive statistics, including confidence intervals of population estimates, were used to summarize the demographic information for caregiving parents, the types of care provided, unmet needs and the impact of caregiving.

Objective 2 (Age-related transitions in caregiving). Aging is a key issue for these caregivers. To examine the relationship of age with various other factors, age was dichotomized into age groups 65-74 and 75+, and examined in relation to caregiving status and to sex (does the proportion of female caregivers change across age groups?). There is also an analysis of caregiving status by age group and urban vs. rural residence.

3.3 Findings/Discussion

Table 3.3.1 shows the unweighted numbers of age 65-74 and age 75+ respondents in the GSS, according to their sex and status as caregivers. It is striking that overall, there were only 46 older parents caring for adult sons/daughters. While not shown in this table, the respondent age group 45-64 included another 18 parents caring for sons/daughters. Note that all of the caregiving referred to in this and subsequent tables is for long-term health conditions.

Table 3.3.1 - Unweighted numbers of respondents age 65 and over, by age group, sex, and caregiving status (n=5,952)

| Age and Sex | | Caregivers to: | | | Non-caregivers | Totals |
|-------------|------------|-----------------|---------|--------|----------------|--------|
| | | Sons/ daughters | Spouses | Others | | |
| 65-74 | F | 20 | 56 | 183 | 1738 | 1997 |
| | M | 11 | 41 | 118 | 1379 | 1549 |
| | Both sexes | 31 | 97 | 301 | 3117 | 3546 |
| 75+ | F | 11 | 25 | 73 | 1500 | 1609 |
| | M | 4 | 15 | 28 | 750 | 797 |
| | Both sexes | 15 | 40 | 101 | 2250 | 2406 |
| All 65+ | F | 31 | 81 | 256 | 3238 | 3606 |
| | M | 15 | 56 | 146 | 2129 | 2346 |
| | Both sexes | 46 | 137 | 402 | 5367 | 5952 |

Table 3.3.2 gives prevalence estimates, based on the data in Table 3.3.1 and on weights provided for use with the GSS. In both the 65-74 and the 75+ age groups, the prevalence of caregiving for sons/daughters is somewhat higher for females than males (0.7% vs. 0.4%). The overall prevalence estimate for age 65+ is 0.6%; given an estimated total Canadian population aged 65+ of about 3,418,000, this means that about 20,000 Canadians are caring for adult sons/daughters with long-term health problems. Although not shown in Table 3.3.2, the estimate of such caregivers among the age group 45-64 is 40,000.

Not surprisingly, the prevalence of caring for spouses is higher than caring for sons/daughters. However, it is interesting to note that this spousal caregiving prevalence rate is highest among age 75+ males. A likely explanation is that there are fewer male spouses surviving in this age group to

be cared for by the females (see Estimated Totals column).

Table 3.3.2 - Weighted prevalence estimates of Canadians age 65 and over, by age group, sex, and caregiving status. Figures are percentages of the Estimated Totals listed at the end of each row. All Estimated Totals are rounded to the nearest thousand; the overall N=3,418,000.

| Age Groups and Sex | Caregivers to: | | | Non-caregivers (%) | Estimated Totals (N) |
|--------------------|--------------------|-------------|------------|--------------------|----------------------|
| | Sons/daughters (%) | Spouses (%) | Others (%) | | |
| 65-74 F | 0.7 | 3.2 | 8.1 | 88.0 | 1184000 |
| M | 0.4 | 2.5 | 7.3 | 89.8 | 918000 |
| Both sexes | 0.6 | 2.9 | 7.7 | 88.9 | 2102000 |
| 75+ F | 0.7 | 1.7 | 3.9 | 93.8 | 880000 |
| M | 0.4 | 3.3 | 3.8 | 92.5 | 436000 |
| Both sexes | 0.6 | 2.3 | 3.8 | 93.3 | 1316000 |
| All 65+ F | 0.7 | 2.6 | 6.3 | 90.4 | 2064000 |
| M | 0.4 | 2.8 | 6.1 | 90.7 | 1354000 |
| Both sexes | 0.6 | 2.7 | 6.2 | 90.6 | 3418000 |

Table 3.3.3 (weighted data) suggests no urban/rural difference in prevalence of caring for sons/daughters among the age 65-74 group, but a higher rate among the 75+ group in rural vs. urban areas (1.1% vs. 0.4%, respectively). By contrast, in both age groups, the prevalence rate of caring for “others” (not sons/daughters or spouses) appears higher in urban vs. rural areas.

The remaining quantitative analyses simply illustrate frequency results from the 46 parent caregivers only. There are no weighted results presented, due to small numbers and limited reliability of weighted estimates under these circumstances. However, it is meaningful and useful to get a more detailed picture of these individuals’ caregiving situations.

For both age groups, only about a third of respondents were married, but about half were widowed (Table 3.3.4). These findings were echoed in Table 3.3.5, showing the living arrangements, where about a third lived with spouses (with or without children), about a third lived with children (mostly single vs. married children), and just over a quarter lived alone.

Table 3.3.3 - Weighted prevalence estimates of Canadians age 65 and over, by age group, urban/rural residence, and caregiving status. Figures are percentages of the Estimated Totals listed at the end of each row. All Estimated Totals are rounded to the nearest thousand; the overall N=3,418,000.

| Ages and residence locations | Caregivers to: | | | Non-caregivers (%) | Estimated Totals (N) |
|------------------------------|--------------------|-------------|------------|--------------------|----------------------|
| | Sons/daughters (%) | Spouses (%) | Others (%) | | |
| 65-74 Urban | 0.6 | 2.9 | 7.9 | 88.6 | |
| Rural | 0.6 | 2.7 | 6.7 | 90.0 | |
| Overall | 0.6 | 2.9 | 7.7 | 88.9 | 2102000 |
| 75+ Urban | 0.4 | 2.4 | 4.0 | 93.2 | |
| Rural | 1.1 | 2.2 | 3.1 | 93.6 | |
| Overall | 0.6 | 2.3 | 3.8 | 93.3 | 1316000 |
| All 65+ Urban | 0.5 | 2.7 | 6.4 | 90.4 | |
| Rural | 0.8 | 2.5 | 5.3 | 91.4 | |
| Overall | 0.6 | 2.7 | 6.2 | 90.6 | 3418000 |

Table 3.3.4 - Marital status of 46 older respondents caring for adult sons/daughters with long-term health problems

| Marital status | Age groups of caregivers | | |
|--------------------|--------------------------|------------|----------------|
| | 65-74 (n=31) | 75+ (n=15) | All 65+ (n=46) |
| Married/common-law | 10 | 6 | 16 |
| Separated/divorced | 7 | 0 | 7 |
| Widowed | 14 | 9 | 23 |

Table 3.3.5 - Types of living arrangements among 46 older respondents caring for adult sons/daughters with long-term health problems

| Living Arrangements | Age groups of caregivers | | |
|--------------------------------|--------------------------|---------------|-------------------|
| | 65-74 (n=31) | 75+ (n=15) | All 65+ (n=46) |
| Alone | 10 | 2 | 12 |
| With spouse | 6 | 3 | 9 |
| With spouse + single child | 4 | 2 | 6 |
| With spouse + non-single child | 0 | 1 | 1 |
| With single child | 7 | 7 | 14 |
| With non-single child | 3 | 0 | 3 |
| Other | 1 | 0 | 1 |

Table 3.3.6 - Types of help provided by 46 older respondents caring for adult sons/daughters with long-term health problems

| Help given | Age groups of caregivers | | |
|---------------|--------------------------|---------------|-------------------|
| | 65-74 (n=31) | 75+ (n=15) | All 65+ (n=46) |
| Child care | 2 | 2 | 4 |
| Housework | 21 | 9 | 30 |
| Shopping | 20 | 6 | 26 |
| Personal care | 7 | 5 | 12 |

(Table 3.3.6). Given the ages of the respondents, it is not too surprising that they, too, received some help. The most common form of help received by the respondents was checking up and emotional support (24 and 20 of the 46 respondents, respectively), but 7 of the respondents required help with

instrumental or basic activities of daily living (Table 3.3.7). This profile highlights the precarious situation of these caregivers, who themselves may need help.

Table 3.3.7 - Types of help received (because of the respondent’s long-term health or physical limitations) by 46 older respondents caring for adult sons/daughters with long-term health problems

| Help received | Age groups of caregivers | | |
|---------------------------|--------------------------|---------------|-------------------|
| | 65-74 (n=31) | 75+ (n=15) | All 65+ (n=46) |
| Housework | 1 | 2 | 3 |
| Shopping | 1 | 3 | 4 |
| Personal care | 0 | 1 | 1 |
| Any (I)ADL | 2 | 5 | 7 |
| Checking (visit or phone) | 15 | 9 | 24 |
| Emotional support | 11 | 9 | 20 |

Table 3.3.8 - What would be most useful in allowing older respondents to continue providing help to adult sons/daughters (n=46)

| Options | Frequency |
|--|-----------|
| Nothing | 22 |
| Financial compensation | 8 |
| Occasional relief or sharing of responsibilities | 7 |
| Information re: caregiving | 1 |
| Information re: long-term illness/disability | 5 |
| Counselling | 1 |
| Other | 9 |

As outlined in Table 3.3.8, when asked which of the options presented might allow them to continue providing help to their sons/daughters, 22 of the respondents chose “Nothing.” Other, less commonly chosen options included financial compensation, occasional relief or sharing of responsibilities, and information regarding long-term illness/disability (8,7, and 5 respondents, respectively). Consistent with these perceived needs, Table 3.3.9 demonstrates some of the changes

over the past year, caused by the respondents' caregiving for their sons/daughters. Nearly half of respondents identified changes in social activities and extra expenses. About a third had moved, or their sons/daughters had moved, to be closer or in the same dwelling. Also identified were changes to Holiday plans, sleep patterns and declines in the respondents' health.

Table 3.3.9 - Changes over the past 12 months, caused by caring for adult son/daughter, in older respondents providing help to adult sons/daughters (n=46)

| Changes in older parents, due to caregiving | Frequency |
|--|-----------|
| Social activities | 20 |
| Extra expenses | 20 |
| Parent(s) or their sons/daughters moved closer or into the same dwelling | 15 |
| Holiday plans | 13 |
| Sleep patterns | 12 |
| Decline in health | 9 |

Table 3.3.10 - Feelings experienced at least sometimes by older parent caregivers (n=46)

| Feelings | Frequency |
|----------|-----------|
|----------|-----------|

| | |
|--|----|
| Negative Feelings: | |
| They do not have enough time for themselves | 14 |
| They should be doing more for their son/daughter | 14 |
| Conflicting priorities cause stress | 12 |
| They wish someone else would take over | 11 |
| Being around [their son/daughter] makes them angry | 10 |
| Positive Feelings: | |
| Helping others strengthens your relationship with those you help | 37 |
| Helping others is giving back what life has given to you | 29 |
| Helping others is giving back what you receive from those you help | 18 |
| Others help them more than they help others | 7 |

In light of these unmet needs, and the changes in their lives that caregiving has caused, some negative feelings are expected. Table 3.3.10 lists some of these feelings expressed by the respondents - including time pressures, guilt, stress and anger - and the numbers of respondents reporting these feelings at least some of the time. What is most striking about Table 3.3.10, however, is the high frequency of positive feelings, and a strong sense of reciprocity.

In summary, from the GSS data it is estimated that in Canada, there are approximately 20,000 parents aged 65 or more, caring for adult sons or daughters with long-term health problems. Following this group are 40,000 parent caregivers in the age group 45-64. Until this analysis, very little was known about these caregivers of adult sons and daughters. Among the older parents, many are widowed and some are themselves in need of help. Older parent caregivers identify financial and respite issues as unmet needs. Yet, despite the apparent problems, these older parents report predominantly positive feelings associated with their roles as caregivers.

4. EVERYDAY EXPERIENCES: QUALITATIVE COMPONENT

4.1 Theoretical Frameworks

The qualitative component of this study was informed by particular theoretical principles. A hermeneutic phenomenological approach was incorporated within the original design of the study. Phenomenology is one of the “family” of philosophical and methodological traditions known as interpretivism. Proponents of this tradition “share the goal of understanding the complex world of lived experience from the point of view of those who live it” (Schwandt, 1994, p. 120).

A phenomenological focus was appropriate at the outset of this study. In accordance with the objectives of the qualitative component of the study, researchers were interested in encouraging participants to speak from their experience so that the everyday aspects of their daily lives and relevant meanings could be recovered and acknowledged. However, as the study progressed, it became apparent that broad social processes were embodied in the everyday lives of participating parents. In particular, concepts of disability, aging, and “family” emerged as not just subjective, idiosyncratic experiences, but as societal phenomena. Researchers began to understand the concepts as *social* practices and not just personal attributes. As a result, the processes constituting disability, aging and family life as categories at the level of society became important to the ongoing progress of this study.

The shift to a social focus meant that researchers were in a position to detect within the words of study participants the broad frameworks wherein certain aspects of aging, family life and disability are in focus and other aspects pushed aside. This privileging of certain aspects over others allowed researchers to understand conceptualizations of aging, disability and family life as inherently ideological and discursive.

Code (1991, p. 96) describes ideology as a set of beliefs, values, and representations that carry meaning for individuals in their everyday lives and which typically embody the interests and position, or the relevances, of a dominant group. Discourses are textually mediated systems of knowledge that are anchored around the ideals of ideology (Hedlund, 2000). As such, discourses and ideologies are inextricably connected. Discursive concepts and categories derive their power from particular ideologies, and at the same time, they reinforce particular ideologies. As researchers analyzed accounts of everyday experience through interviews with the older parents participating in this study, the ways in which their conceptions of their daily lives with their adult sons/daughters were ideologically and discursively organized became clear.

Participating parents described social representations denoting collective norms ascribed to their lives. It was clear that these classifications were not arbitrary, but embedded in power and resulted in archetypes about what is considered to be the “truth” about their lives. The historical and contextual framing of the “truths” defining disability, aging and family, and the relationship among

the three, was also visible through analysis of the words of participating parents.

The shift in focus from personal and interactional experience to the level of social representation necessitated the expansion of the theoretical framework underpinning this study. Understanding the embodiment of ideology and discourse within the everyday lives of older parents participating in the study and the dualities that emerge between the everyday and the social meant that components of critical theory became relevant to the analysis ongoing in the study. Specifically, Smith's notion of the "line of fault" became an important lens through which to view the experiences of participating parents.

The "line of fault" is a geological metaphor (Smith, 1987) depicting a point of rupture between prevailing ideologies and the everyday worlds that those deemed to be subordinated through the social relations of race, class, gender, age, ability or sexual orientation experience directly. Smith and other feminist scholars (Campbell & Manicom, 1995; DeVault, 1990b; Harding, 1991) who employ this metaphor to inform their research with women, assume that this rupture opens up a space in individuals' lives between their experiences and dominant ideological and discursive schemes. Moreover, these scholars claim that the line of fault can be experienced as a "bifurcated consciousness" (Smith, 1987).

The experience of a bifurcated consciousness means that perspectives of everyday life may contain two separate, dichotomous, sometimes conflicting themes. One of these is framed in the discursive concepts and categories which embody ideological relevancies and the other is informed by the more immediate realities of everyday life. When experience does not fit within the concepts and categories, alternate concepts may not be readily available. As a consequence, individuals in this position may, sometimes subconsciously, mute *their own* thoughts and feelings when they perceive a "lack of fit" between what *they* know about their everyday lives and what ideology and discourse dictates they *should* know and think and do.

The concept of the "line of fault" as well as the related concept of bifurcation have methodological and epistemological implications for this research. Assuming that ideologies and discourses are embedded within the everyday lives of the older parents and that there is a silencing or a muting of voice in the face of a lack of fit between these ideologies, discourses and the practices constituting their everyday lives, it is reasonable to conclude that, as a result, little would be known about what happens in their everyday worlds.

As a corrective to this, researchers involved in this study used participating parents' experiences in their everyday worlds as the starting points for the research. The study was located within and proceeded from the "local and particular" (Smith, 1987) worlds that the older parents experienced directly rather than from a broader ideological or discursive standpoint. In so doing, absent voices and absent meanings were recovered and rendered visible epistemologically. With this, a "problematic" (Campbell & Manicom, 1995; DeVault, 1990a, 1990b; Smith, 1987) emerged.

A "problematic" is a property of the social organization of the everyday world and is latent in the

actualities of that world (Smith, 1987). This study illuminated the problematic, or the invisible practices characterizing the everyday experiences of participating older parents and their adult children with disabilities. Concomitantly, this research mediated the disjuncture or “line of fault” between the daily practices of the parents and broad ideologies and discourses. Moreover, through analysis, researchers could trace the ways in which ideologies and discourses were embodied within the local settings comprising everyday life. As a result, the analysis has enhanced the understanding that ideologies and discourses of ageism, familialism, and disability are not simply “out there” and acting upon the older parents and their adult children in their everyday worlds, but are actually present in those worlds and rendered visible through the explication of particular practices.

In this study, the invisible practices and the ideologies and discourses embedded within those practices that constitute the “problematic” inherent within the daily lives of participating parents have been brought into view. This has facilitated the development of a critique of the ideologies and discourses relevant to the lives of these parents and others in their position.

4.2 Methodological Process

The collaborators, community organizations and service providers informed their members/clients through newsletters, meetings and personal contact about this research project. Through these contacts, parents voluntarily came forward to participate in this study. The information gathered reflects the perceptions, understandings and realities of this convenience sample of older adults caring for their sons/daughters with lifelong disabilities. The project intended to interview 10 families from each of the Atlantic provinces but due to significant interest, over 60 interviews were conducted, with 56 families meeting the project criteria. This large sample size brought forth a diversity of experiences of families caring for their adult sons/daughters with lifelong disabilities.

Participants in this study were interviewed at one point in time using an unstructured interview guide (Appendix 2). Consistent with the principles of qualitative research, the interviews were conducted intersubjectively. Accordingly, the interviews did not resemble linear exchanges whereby the researchers asked questions and the subjects responded. Rather, the interviews were bi-directional and prompted a give-and-take, a movement back and forth between researcher and participant that was fluid and interactive (Erlandson, Harris, Skipper & Allen, 1993). Essentially, the intersubjective interviewing constituting the qualitative component of this study involved a shift from “...information-gathering, where the focus is on the ‘right’ answers, to interaction, where the focus is on process, on the dynamic unfolding of the subject’s viewpoint” (Anderson & Jack, 1991, p. 23).

The interview questions were simultaneously focused “...inward and outward, backward and forward...” (Clandinin & Connelly, 1994, p. 417). This approach to the construction of interview guides in qualitative research is appropriate when research is aimed at studying personal experience. Clandinin & Connelly (1994) define this approach to interviewing as follows:

By inward, we mean the internal conditions of feelings, hopes, aesthetic reactions, moral dispositions and so on. By outward, we mean existential conditions, that is, the environment...by backward and forward, we are referring to temporality, past, present and future. To experience an experience is to experience it simultaneously in these four ways and to ask questions in each way (p. 417).

This approach was considered in designing the interview guide (Appendix 2) employed in this study. The guide includes questions which focus on retrospective and historical experiences as well as internal, existential and relational conditions. The interview guide was also constructed to help identify significant gaps evident within policies and programs related to aging and disability.

The interviews were taped and transcribed. Transcriptions were sent back to research participants so as to permit revision or re-evaluation of individual contributions. This reflexive process is a reflective process known to as “member checking” designed to reinforce the self-determination of research participants as well as to help ensure the trustworthiness of the data.

Other reflexive processes were used throughout the study. It was important to journal personal perspectives while preparing some field notes after each interview in an effort to work through responses to the research experience. Journaling is recommended by feminist qualitative researchers as a means of ensuring that the researcher does not layer his\her own perceptions and experiences on that which is heard and interpreted in the research process.

Transcriptions were analyzed using the “Non-numerical Unstructured Data By Indexing, Searching and Theorizing (NUD*IST) software. This computer program sets up separate and linked systems for data and an index of ideas about them. It provides the option to structure the index system in a hierarchal “tree” of categories and subcategories (Appendix 3).

NUD*IST emulates mechanical methods for analysis such as Glaser and Strauss’ (1967) “constant comparative method”. This method facilitates the analysis of qualitative data through a process of “constant comparison” among groups, concepts and observations. While the NUD*IST program facilitates coding and retrieval processes which support the development of in-depth descriptions of data, it also permits theory construction. Ideas, concepts and categories which emerge from the data can be “woven by researchers into fabrics of theory” (Richards & Richards, 1994, p. 445).

4.2.1 Justification of Methodology

The methodology utilized in this study was appropriate given that it enabled researchers to use the older parents’ experiences as the starting points for the research. Researchers were able to work with the participants in such a way that the often-invisible daily practices characterizing the *work* of caring for adult sons and daughters with disabilities and the meanings associated with this work were rendered visible. In so doing, absent voices, meanings and experiences related to aging, disability and the relationship between the two were extricated from the “line of fault” separating their daily lives and broader social processes.

Through use of this theoretical and methodological framework, researchers were able to articulate the daily work characterizing the lives of these older parents to discourses of disability and ideologies of ageism and familialism. This facilitated an understanding of the embeddedness of ideology and discourse in the daily lives of participating parents. Locating these ideologies and discourses within everyday life facilitated the development of a critique of the embodiment of these ideologies and discourses within programs and policies in place for older parents caring for adult sons and daughters with disabilities.

Community collaborators were central to the implementation of this methodology. Recent research emphasizes the importance of linking researchers with community collaborators at the conceptual stage of the research process and beyond. Such linkages encourage the utilization of outcome data and facilitate the translation of these data into policy (Lomas, 2000; Plouffe, 2000; Leseman, Manga & Lewis, 1997).

The collaborators who participated in this study provided the lens through which understandings gleaned through the study were filtered. Moreover, the collaborators played a role as advisors to the research team; served as links to provincial policy representatives; assisted in the identification of research participants; and will provide input into the development of relevant programs and policies affecting older parents and their adult sons/daughters with disabilities. The collaborators have also played a key role in the dissemination of the results of the research to date, specifically through co-sponsorship of provincial public forums for decision-makers, program planners, service providers and families in each of the four Atlantic provinces.

4.2.2 Ethical Safeguards

Ethics approval was obtained for the project through Mount Saint Vincent's Ethics Review Committee in accordance with the Tri-Council Guidelines. Study participants were informed that taping of the interviews was not mandatory and they could request that the tape recorder be turned off at any time. The fact that the tapes were stored in a secure location and were only accessed by members of the research team was also clearly noted. Participants were also assured about the maintenance of confidentiality through the use of pseudonyms and the revision of all other potentially identifying information contained in the interview data.

Transcriptions of the interviews were mailed back to research participants for review. This ensured that participants were comfortable with the content of the interview. These considerations were specified in the participant consent form (Appendix 1).

4.3 Profile of Participants

Interviews with 56 families involved a total of 76 parents (mothers and fathers) who were providing various levels of care for a total of 64 adult sons/daughters with developmental or psychiatric disabilities. In two families there was a dual diagnosis of both developmental and psychiatric conditions. It is important to note the following tables display the characteristics of the parents and their sons/daughters who participated in the qualitative component of this research and are not intended to represent the general population.

Table 4.3.1.1 Profile of Older Parents Caring for Adult Sons/Daughters with Disabilities

| Characteristics | Percent |
|--|-----------------------|
| Person(s) Interviewed (N=56 interviews) | |
| Mother only | 59% |
| Mother and Father | 36% |
| Father only | 5% |
| Age of Parent Respondent (N=76 parents) | |
| 60-69* | 32% |
| 70-79 | 50% |
| 80-89 | 14% |
| 90+ | 4% |
| Marital Status (N=56 interviews) | |
| Married | 57% |
| Widowed | 39% |
| Single/Separated/Divorced | 4% |
| Province (N=56 interviews) | |
| NS | 35% (20 interviews) |
| NB | 20% (11 interviews) |
| PEI | 20% (11 interviews) |
| NF | 25% (14 interviews) |
| Location of Interview (N= 56 interviews) | |
| Urban | 44.6% (25 interviews) |
| Semi-urban | 8.9% (5 interviews) |
| Rural | 23.2% (13 interviews) |
| Semi-rural | 17.9% (10 interviews) |
| Remote | 5.4% (3 interviews) |

* One criterion for participation was that at least one parent had to be 65 or older.

Table 4.3.1.2 Profile of Sons/Daughters with Lifelong Disabilities *

| Characteristics of Sons/Daughters (N=64) | Percent (number) |
|---|------------------|
| Gender | |
| Male | 62.5% (n=40) |
| Female | 37.5% (n=24) |
| Age | |
| 20-29 | 12.5% (n=8) |
| 30-39 | 30% (n=19) |
| 40-49 | 50% (n=32) |
| 50-59 | 6% (n=4) |
| 60-69 | 1.5% (n=1) |
| Type of Disability | |
| Developmental | 86% (n=55) |
| Psychiatric | 11% (n=7) |
| Both Developmental and Psychiatric | 3% (n=2) |
| Living Arrangement | |
| At home with parents | 76.5% (n=49) |
| Group Home | 9.5% (n=6) |
| Institution | 1.5% (n=1) |
| Other (own apartment, boarding home, with other family) | 13% (n=8) |

* The number of adult sons/daughters in each family varied from 1-3.

As these tables show, the families who participated in the interviews came from diverse backgrounds and experiences. However, through the interview and analysis process, it became clear that these families share similar types of challenges/experiences such as support for the family, interactions with the health system, etc. Each family has made decisions/choices based on the context and realities of their own lives. The following sections displays the shared themes arising from the interviews through two different but complementary perspectives: age-related transitions and parent-child relationships. The age-related transitions focuses on issues affecting the family as the parents and adult sons/daughters experience aging. The parent-child perspective focuses on the family dynamics emerging from caring for a child with lifelong disabilities. Together these perspectives inform our understanding of the present realities facing these families. This increased understanding can inform public policy to ensure polices meet the needs of these families.

Parents interviewed wanted to have their voices heard - their words are powerful. Italics have been used to signify when direct quotes from the interviews have been included.

4.4 Age-Related Transition Themes

The extensive interviews with parents, occasionally including other family members, yielded a significant store of contextual information about everyday practices and experiences of aging parents who are caring for an adult son/daughter (also aging) with a lifelong disability. Embedded within their stories is evidence of broader societal ideologies of family, age, and disability. The following themes are discussed in this section: reciprocity; centrality of the family; different paradigms for families and system; uniqueness of families; small social networks; different issues in care of adults with developmental disabilities and psychiatric illness; health and social age-related transitions; barriers to future planning; inequities in funding arrangements; and challenges in relationships. Section 4.5 focuses specifically on the themes relevant to parent-child relationships.

4.4.1. Reciprocity

Contrary to the perceptions that the parents caring for adult sons/daughters with lifelong disabilities generally feel overburdened and overwhelmed, the parents in this study expressed predominantly positive feelings, regardless of the level of care. There were a few parents for whom the experience was not positive and it appeared to be related to the disposition of the offspring. Generally, parents described both tangible and intangible benefits resulting from the relationship that can be understood in terms of reciprocity, indicating that their offspring gave back to them and to other family members love, support and acceptance. There were some differences in families providing care to adults with mental illness as compared to those with intellectual disability. For example, the unpredictable nature of the illness and in some instances, fear of aggressive behavior, may engender more anxiety and stress.

Parents were asked to share what they believed their sons/daughters with disabilities brought to their families. This almost always elicited a range of intra-psychic benefits that spoke to personal and familial meaning systems. As one mother said:

“Love, I suppose, and in some respects someone to care for and see that he’s protected and looked after and... fun, too. You know, we have lots of laughs and we do things together and it’s companionship for me too.”

While many parents did speak of positive elements, they did not gloss over some of the challenges. They recognized that difficulties exist, as expressed by one mother: *“Some pain, some happiness”*. Thus contributions to the parents and the families can be both instrumental and/or affective.

Instrumental Contributions. Adults with lifelong disabilities make many and varied contributions to their parents through the provision of instrumental assistance and by providing expressive support (Greenberg, 1995; Greenberg, Greenley, & Benedict, 1994). Tangible benefits of household assistance emerged in discussion about what the son or daughter does to help the parent. Parents were appreciative of the tangible support provided by their sons/daughters, acknowledging the real help it offered them and perceiving that it provided the son/daughter with a sense of satisfaction:

“She loves to help”; *“He felt really useful”*; and *“...[daughter] always wants to be doing things, and she loves doing things for other people”*. There was a range of activities performed by the sons/daughters. They helped with meal preparation, housework such as vacuuming, dusting, making beds, folding clothes, washing dishes, keeping own bedroom clean, and sometimes laundry. This assistance was appreciated by parents who may have been experiencing some functional limitations from age-related chronic conditions. Generally, although there were exceptions, the assistance from adults with intellectual disability did not involve use of sophisticated machines. The assistance with mundane household chores was generally carried out under watchful supervision from the parents who also set the parameters on ‘what was allowed’. The assistance provided by the sons/daughters offers insight into social support for aging parents.

Routine and order are very important for persons with intellectual disabilities and chores become part of everyday life, offering a source of satisfaction to the adult child and a valued support for the parents. In some cases, this support was a key element in the family being able to stay in their home, particularly when a parent develops a health related restriction on activity. In one family, the mother’s osteoporosis prevented her from chopping kindling, or lifting and carrying heavy objects and the son’s help with those chores meant that they were able to stay in the family home where the wood stove was a primary source of heat. For those with mental illness, the routine was less of a factor, and the reliance on the support from the child not as certain. The participation in activities was very much dependent on the extent of the illness at any point in time. This was illustrated in one family where a son, when well, was able to drive the mother to different places. In our study, eight of the nine offspring diagnosed with mental illness happened to be male so it is not possible to investigate the impact of gender in those families where the disability is psychiatric in nature.

Affective Contributions. Caring for adult sons/daughters and meeting their needs may confer a sense of purpose or usefulness and impart structure in the lives of parents (Gubman & Tessler, 1987). Tobin (1996) suggests that parents who care for adult sons/daughters with lifelong disabilities gain an identity and meaning from this role that eludes other parents. In our study, many spoke of the sense of purpose they felt and we found that the parenting role was central, in a particular way, to the lives of parents: *“Well, I just couldn’t imagine my life without her...”*, and *“...well, I guess it fills up my role in life”*. They derived pleasure from their offspring despite obvious challenges. As one mother of a son with schizophrenia who has been relatively well for awhile said: *“He’s a joy. It was a long haul but it was a worthwhile long haul. I enjoy him more than I’ve ever enjoyed him because we could never do with him what we wanted...”*. Another said of two disabled offspring: *“...they’ve given us a lot of pleasure.”* While parents of able-bodied children also have these feelings, the longevity of the active parenting/caregiving role and the ongoing responsibilities for daily care induced different experiences for the parents in our study.

There was a sense of empowerment indicated in the comments of some parents resulting from a visible ‘reward’ for their good care evident in the health and functional achievements of their sons/daughters. Parents had often been told in the early years of their child’s life that their sons/daughters would live only a few years, or would not walk, talk or be able to learn, and when their offspring’s growth and development defied these pessimistic prognoses, parents knew that their

persistence and commitment had been a major factor: “...if we had left her there, she would have died.”

The contentment of a well-developed bond over time may be under-recognized for these parents. The parent/child relationships commonly appeared very strong, permeated with affect, mutuality, and connection - all the hallmarks of healthy relationships. It was evident the feelings between parents and offspring were mutual and complex. This challenges the vague sense underlying some common perceptions about these relationships that because the child has a disability, somehow the relationships are ‘disabled’ or one-way. There was the comfort of unconditional love (“...he just thinks his parents are the best.”) and a relative stability in the roles of parents caring for adult sons/daughters with intellectual disability.

Within relationships, gift-giving is one way of expressing affection and has become entrenched in traditional rituals for many holidays. In our study, parents reported that they were the recipients of very thoughtful and creative gifts from their sons/daughters and parents perceived that the choosing, making, and giving of gifts to parents, families and friends was very important to the offspring. One son spent a month’s wages from his workshop to purchase a special gift of a theatre ticket for his mother to a play she really wanted to see. To his mother, this was a very touching expression of his love.

As with all parents, there are intrapsychic benefits resulting from a sense of pride in the accomplishments of their child and a rejoicing in the recognition that a child may receive. These parents spoke of accomplishments of their offspring in Special Olympics. They spoke also of particular skills and talents that were valued by the family, such as a great memory or an ability to predict weather which was very important to one native family given the centrality of natural phenomenon in their culture, and a strong work ethic reflected in compliments from work placements. They were pleased when their son or daughter was accepted by others around them. Appreciation from the offspring in response to everyday care, and a pleasant disposition, helped the parents form positive perspectives.

Parents presented a balanced perspective; they did not gloss over the challenges and the difficulties but rather, situated them within a broader relationship context. One mother’s comment poignantly reflected this: “*She’s a responsibility, but she’s not a burden.*”

Contributions to the Family. When asked what the sons/daughters with disabilities bring to the family, parents were quick to identify concepts that reflect an enhanced sense of social responsibility, ideas such as “...she’s made us more compassionate”. One sibling commented: “*I feel I can give of my experience to others*”. Another said: “*He has taught us what no education and worldly thing will ever teach us.*”

Parents’ comments suggest that their sons/daughters with disability can be pivotal points for family interaction: “*Everything that happens to [daughter], everybody wants to know.*”, and “*That’s exactly what she is - centre of communication*”. A great deal of family communication between

adult children and parents focused on the well-being of the person with disability, any changes in their health status, any new experiences they may have had, arrangements for care if the parent is temporarily unable to be there and to a lesser extent, discussion about future care. An unexpected outcome for the parents is increased social support and interaction. Canadian families generally have frequent interaction among members; an interesting area for future research would be the patterns of interaction in families with an adult child with lifelong disabilities. Frequently, parents and siblings who were present in the interview mentioned that the son/daughter can serve as a reason for family to stay bonded “...*she kept us all together close*”.

Sons/daughters with special needs frequently stimulated personal growth and awareness within family members. Parents spoke of their family members being taught patience, unconditional love and most of all acceptance of others’ limitations. Some believed that stronger family bonds developed between parents and offspring, and among siblings, as they stood up for their brother or sister in play and school. Parents believed that teachers, if they were open to it, learned from those with disabilities through participation in the class. As well, it was evident that some of the siblings chose careers in a sector relevant to the health or social needs of their brother or sister. Their personal experience offered them a unique vantage point.

There has been little discussion in the literature about the bonds that develop with nieces and nephews. Parents and siblings described special relationships that existed between the person with disability and grandchildren of the aging parent. The person with the disability has the time and interest to interact with other family members.

Contributions to Society Through Advocacy. A positive outcome that is infrequently acknowledged was evident to the researchers in the contributions of parents and other family members to the larger society, primarily because of their own experiences. Parents were strong advocates for their offspring and in their constant ‘fight’ to obtain services for their own child, found themselves embroiled in a larger context that benefitted other families, “...*sharing with other people who are in the same boat.*” Letters to the media, appeals to elected officials, public presentations, ‘hands-on’ development of new facilities, programs or services, and in one case, consideration of legal action, were some advocacy strategies that were utilized. Parents took leadership roles on local, provincial and national levels. Their efforts were visible in health, social and educational arenas, resulting in shared knowledge, new programs, special classes, and funds for facilities. Parents’ advocacy efforts led some to begin parents’ groups to address issues of social, residential and legal/financial needs of families. In all cases, the parents’ advocacy and commitment sprang from an initial desire to respond to unmet needs of their own sons/daughters in their everyday experiences but grew in response to the realization that the needs were those of many. Many older parents in our study created community legacies with their efforts and now indicated that they were ready to hand the responsibilities for social action over to others.

4.4.2 Centrality of the Family

Parents’ stories revealed the centrality of family in the care and support of those with lifelong

disabilities, affecting every aspect of each others' lives over a period of several decades. The majority of sons/daughters in our study lived at home with their parent(s) who were the main source of instrumental and affective support to the sons/daughters - sometimes the only source. Even when the sons/daughters moved into another residential option, parents and other family retained a significant role in ensuring that they were receiving good care, providing a break during weekends or holidays, and ensuring that the sons/daughters were included in the family news and interactions. In addition to being a source of strong family bonds, the centrality carried with it some inherent risks and could be a source of stress for the family members. An inability to provide care on the part of the parents disproportionately affected the immediate well-being of the offspring, sometimes necessitating emergency care arrangements. Conversely, a change in the care needs of the sons/daughters could also disproportionately affect the aging parents' capacity by tipping the balance between these needs and what the parents could manage within the constraints of their own limitations.

The key message that emerged is that the system is well advised to adopt a 'family lens' in its approach to services. Initiatives that support the family's capacity to provide care, and recognize that changes occur over time, can mitigate the effects when something goes awry. Parents have a major role in ensuring the well-being and day-to-day care of their sons/daughters with disabilities, despite the reality that their expertise is often not included in policy development and implementation. While well used to the routine of many decades of care, both the parents and the sons/daughters face new challenges that emerge with aging and their experience needs to be reflected.

4.4.3. Different Paradigms For Families and Systems

Older parents and the 'system' operate from dramatically different paradigms, thus, philosophies, values, goals and expectations may not be 'in sync'. Parents speak of function rather than disability, referring to the capacity of their offspring to do particular activities or to respond in a certain way. They seldom name the disability unless specifically asked. Those in the system, adopting a macro approach, often use the concept of specific (or general) disability as a screening factor in determining eligibility for services.

Older parents have low expectations of the system based on their experiences over time. They have advocated for many changes, requesting supports and recognition of their sons'/daughters' rights to a quality of life that other citizens take for granted, and have experienced many disappointments. Their voices are seldom heard nor included in policy decisions. Given the age of the parents and offspring in our study, their perceptions have developed over many decades. They have observed the ebb and flow of changing philosophical paradigms, policy and program reconfiguration, budget revisions and changing political platforms. Through this constant maze of change, their day-to-day routine continues, resulting in a sense that they can ultimately only depend upon their own resources or those of other family members. This sense is heightened by an Atlantic Canada culture of privacy and independence. In addition, there can be a lack of trust and rapport between service providers and families, particularly where parents have asked little of the system over time and now when they have changing needs, the system is not prepared to assist them. Many of these older parents were advised

several decades ago to place their son or daughter in an institution and ‘walk away’. Because they did not choose this prevailing option at the time, these parents, who were pioneers in community-based care, did not develop images of collaboration between service providers and families unless they have had positive experiences in later years.

The differences in language, experience, and priorities can set up formidable barriers between parents and the ‘system’ sometimes resulting in adversarial, rather than collaborative, efforts. As one parent commented: *“I’m not really exaggerating that it is a continuous struggle and the changes come little step by little step. But if you stop fighting...”*. Those in the system must address the concept of trust-building as well as service provision.

4.4.4. Uniqueness of Families

Every family has its unique footprint. For the families in this study, their uniqueness was often defined by others in terms of the disability, making them isolated within their communities. A mother noted the reality by saying: *“Families come in all shapes and sizes. Ours may look a little different from others...”* The heterogeneity of families is often not recognized in policy interpretations, resulting in a lack of ‘fit’ between the system and the families. Family dynamics, specific circumstances, nature of disability and availability of informal social support all affect the parents’ need for services.

4.4.5. Small Social Networks for Support

In this study, the network of older parents were frequently small, predominantly comprised of immediate and extended families and a few friends. The heavy demands of care often meant that parents had to forego social events because their sons/daughters could not be included, they could not get respite or they just didn’t have the energy. As well, it was not easy to make arrangements in some situations where special equipment, facilities or attention was needed. It was easier to stay at home. Some of the parents had developed close friendships with other parents caring for adult sons/daughters, offering a web of support to each other. The study did not explore the perceptions that parents attributed to the size of their networks - whether small networks were perceived as positive or negative. It is mentioned in this report because as the networks shrink when people age and/or pass on, a large void is created in social support. Some parents referred to the death or chronic illness of people who had been a major support to them, indicating that they now had to seek other alternatives for support. However, the effectiveness of existing support is a better indicator than the actual size of social support network as it determines the quality of support available. This concept was not explored with the parents.

Striking, although not surprising, was the evidence of the very limited social networks of the adult son/daughter. The sons/daughters socialized mainly with their parents and sometimes with other family members, occasionally in organized events with other adults who also had disabilities. They seldom had opportunities to socialize in the general community or with their peers. This finding reinforces the centrality of family theme. Parents are very aware of their position in their

son/daughter's life, adding to the difficulty of decisions around alternative living arrangements. Only one of the 64 sons/daughters in our sample was married and one had been engaged for 2 years.

Support from the formal sector was very limited for these families. Professionals and service providers had large caseloads and so it was often only those with the most acute need who received limited services. Some parents accessed services for respite but availability and times varied across and within the provinces. The systemic barriers are very effective in discouraging use of services, particularly as it is clear that parents do not ask for help easily or readily.

The stories of these families indicate that little is known about their life course experiences, a finding that is also supported in the literature. Parents often found that professionals in health care fields, particularly dentistry which was mentioned by many of them, had limited knowledge about routine care for persons with lifelong disabilities as well as age-related changes. When specific health problems emerged, parents were expected to be able to respond despite the fact that little help was offered to them. Parents are seldom asked about their needs and so rarely share their needs with professionals and service providers.

4.4.6. Issues in Care of Adults with Developmental Disabilities and Psychiatric Illness

It was evident from the parents' experiences that there were very different challenges when their son/daughter had a psychiatric disability (14% of our sample) as compared to developmental disability (86% of our sample). Three per cent of this sample had a dual diagnosis of both developmental and psychiatric disability which presents significant challenges in obtaining services and professional help. With psychiatric disability periods of illness could be interspersed with periods of relative wellness so the care needs fluctuated greatly. A mother commented: "*When he slips, I can see it. But sometimes it only lasts a week and he's up again and you know, working again.*"

Much of the challenge comes from the unpredictability in behavior of those with psychiatric illness, sometimes imbuing the situation with some anxiety and uncertainty. There is a relative consistency in behavior and predictability of affect among those with developmental disabilities. Most of those with psychiatric disabilities lived outside of the parents' homes whereas most of those with developmental disabilities remained in the home. Aggression was sometimes a factor in seeking alternative housing often becoming more of an issue as parents age and felt that they could no longer manage the aggressive behavior. As well, the parents of sons/daughters with severe mental illness were less likely to expect their other offspring to assume the caregiving role.

Particular issues arose for families because of the paucity of mental health services and for many, the inadequacy of services meant that other systems were called into play. Parts of the justice system (i.e. police, RCMP) were often involved when there was disruptive behavior because there was simply no one else to respond.

4.4.7. Health and Social Age-Related Transitions

Health. Aging is a normal, gradual process that calls for various adaptations and sometimes goal adjustments to accommodate changing abilities. In the absence of disease, most people while experiencing age-related changes in each body system, retain the capacity to participate in the things that are most meaningful to them. The older parents interviewed in this study identified various functional outcomes of changes they noticed over the years. As expected there was a variety of conditions associated with later life such as diabetes, heart disease, arthritis and sensory deficits. However, many expressed that as long as their “health” remained good, they wanted to continue the care they were providing. Many of the parents indicated they were experiencing chronic health conditions, however, they measured their health in terms of their ability to function. For these parents, the care was an ordinary part of family interactions and a long established routine and a they adapted their routines to accommodate changes in their abilities.

The significance of health problems to the parents was linked to the impact on their ability to continue to provide care, consistent with the centrality of family care to the well-being of those with lifelong disability. Parents found themselves making choices about the activities in which they would engage, affirming the Baltes & Baltes metamodel of selective optimization and compensation which proposes that as energy diminishes people select the things they wish to do, direct the energies in that manner and compensate for the losses in other areas (Baltes & Carstensen, 1996). Parents spoke of limited energy, difficulty in lifting and often, concern about an emergency if something suddenly happened to them. In most cases, unless the functional changes resulted from a sudden illness, the changes did happen over a period of time and the parents established creative ways to respond. For some families, it was a time when sons/daughters were encouraged to take on a bit more responsibility. For others, the move of the offspring to alternative housing had already occurred because the parents were no longer able to manage the demands.

A particularly major issue for families arises if the parent can no longer drive, or if a parent is widowed and had never driven. This is more likely for women. Given the reality of appallingly inadequate transportation services in most areas of the Atlantic provinces, this could be a very isolating phenomenon. Grocery shopping, rather than a routine chore, becomes a big challenge, not to mention other necessities such as medical appointments. Participation in faith communities and in social activities can fall to the bottom of the priority list.

Knowledge about healthy/successful aging refers frequently to the necessary prerequisites of meaning and purpose. For these parents, the elements of meaning and purpose were clearly present in their lives and the holistic care of sons/daughters was an integral source of identity for them. In many cases, it appeared that their day-to-day responsibilities, rather than being a burden, actually motivated and energized them. This observation offers an interesting area for further research.

The adult sons/daughters were also experiencing age-related changes, often presenting unique challenges. The literature reveals (Janicki, 1999) that those with particular lifelong disabilities may experience accelerated aging accompanied by age-related health problems. For example, persons with Down Syndrome are more likely to develop Alzheimer Disease than the general population and its onset is at earlier ages (Zigman, Seltzer & Silverman, 1994). Some of the sons/daughters had

begun to experience seizures, multiple medications, diminished energy, shortness of breath, and loss of mobility. This increased need for care often was more of a focus point for families than the changing needs of aging parents. A few parents noted that as their son/daughter aged, their attention span increased as well as their capability. Some whose offspring lived outside the home also noted some improvement in behavior. These very different experiences of sons'/daughters' aging support the need for flexibility in formal social support options to reflect each family's reality.

Two issues were frequently mentioned in the context of inadequate information and training for health care providers and families. Both dental care and menstruation, ordinary aspects of our lives, created interesting challenges for families. For those aging with lifelong disabilities, communication difficulties and/or intellectual disabilities complicated the process of reporting symptoms and understanding preventive and treatment measures. Many professionals have little training in providing routine (or even non-routine) health care services to those with complex disabilities, leaving the parents to be vigilant advocates for even basic services. Inadequate responses to health care needs often meant that the presenting issues escalated (e.g. 'hot flashes' can be quite disturbing when they are not understood as an expected part of menopause). Lack of adequate dental care has significant implications for overall health, particularly for those who may be prone to dental problems because of their disability.

Social. Aging is both an individual and social process. As the parents aged, so did those around them - those who comprised their support networks. Many families faced the new worry of seeing their own support systems change - family members (or friends) were no longer able to provide back-up care. This creates a new concern about what would happen in an emergency:

It's being the care.. just being the sole support for her right now is the biggest concern of mine, that if I got sick where would I go for help. I mean she has a great aunt down there, she's 75 though. And we.. I know the neighbours would look after her, but they're all old. And she's great friends with the neighbor next door, and she's 84.

Others became increasingly aware of their shrinking networks of friends. A few of the families interviewed had no relatives in the area, depending instead on networks of friends or formal services for assistance. This situation is exacerbated by the out-migration seen in many rural areas of the provinces.

While many of the families had several offspring, they were often dispersed around the world. However, many parents did have at least one other son/daughter who lived relatively nearby and on whom they could count for support. They also were aging and experiencing their own challenges. Many of the siblings of the person with disability were entrenched in careers with their own growing families. Interestingly, some of the parents commented on the fact that as their other sons/daughters retired they may take on an increased role in care for the person with disability. Again this challenges us to use a different lens in viewing these families as the age-associated change of retirement can generate a renewed resource of support for some families. Retirement of sons/daughters with disabilities is also an emerging issue for families and society as sons/daughters may need to cut back

on workshop participation because of functional changes. Retirement is not usually planned with this population and has been receiving a great deal of attention. The issue also affects the group home providers and challenges them to restructure their programming; currently the intent is that the residents of the group homes would be participating in an outside activity during the day.

A major transition for older families is that of widowhood. Almost 60% of our sample were already widowed. Those who were still married frequently mentioned that they did not know how they would manage if the other spouse 'went first': "*If something happened to [husband] that's it. I'm.. I won't be able to take care of [son].*" Husbands and wives most often shared the care to various degrees, with increased responsibility of the husbands in care activities often occurring after retirement. A few husbands who took on increased care responsibilities, or assumed them after the wife's death, commented that they did not know how their wife had managed all those years. In two families where the father was widowed, the wife's death triggered an increase in formal services, something that was not evident in families where it was the wife who had been widowed.

In our study, there were only 4% who were separated or divorced. This low proportion appears to be a cohort effect as it is similar to this age group in the general population.

Housing was frequently mentioned by the parents, primarily by widows or in families where one spouse had health challenges. In some of these situations, the issue was raised in terms of recognizing that they may not be able to remain in the home and they were exploring options for housing for themselves and their sons/daughters. For some, this also was a transition point to exploring alternative housing for their offspring. In many cases, parents expressed that they wanted to hold on to the house so that their sons/daughters could remain in the home they always knew. One parent said that by keeping the house, he felt that it would be a central point for other siblings (who lived 'away') to encourage interaction. Another indicated that while they offered the house to other siblings in exchange for care of the disabled sibling, there were no takers.

Parents expressed that they were acutely aware that their sons/daughters did not react well to change - a factor that was also a barrier in future planning: "*[Son] won't survive with strangers.*" This was often a motivating factor for the parents to remain in the family home long after they might have if there was only themselves to consider. For the most part, families lived in older homes in the four provinces where they resided for many years. Older homes often have steeper staircases and frequently lack a bathroom on the main level which can present challenges. Some families had converted a downstairs room to a bedroom to accommodate changing needs. Rural areas also presented challenges, such as limited services to respond to changing needs.

4.4.8 Barriers to Future Planning

A paradox exists around the issue of future planning. While there is universal concern about 'what will happen to my son/daughter when I'm gone', there is minimal action taken to put plans in place. Many studies have examined why this is the case, seeking to understand barriers. In this study, many of the known barriers emerged, however, they seemed to be shadowed by a strong theme that what

the parents wanted had much more to do with quality of life than with the tangible elements of care provision. The issues of a roof over their son/daughter's head and financial support were layered by their desire that their son/daughter be truly 'cared' for, in a 'home-like' environment, in the sense of being valued and respected with opportunities for meaningful activities. And they weren't seeing these options existing. In our study 14.3% of the parents were caring for more than one son/daughter with lifelong disabilities, often with minimal external assistance. In these situations many of the parents wanted to keep the siblings together, creating an even bigger challenge for future care.

Planning involves the four domains of residential care, legal responsibility, financial support and social opportunities. Within these domains are embedded needs for ongoing health care, personal support, decision-making and money management. None of the families had a comprehensive formal plan in place involving all domains. Many families had no plans in place, although some were considering taking some steps and others had talked about it with family members. For those with specific plans, it may be in only one or two areas. When asked if it was a concern, some parents responded that it was in "God's hands". Most expressed the worry it generated as they just didn't see an effective solution available. One mother said:

My son knows it all and it's all going to be down in writing. If I can get it on the computer, it will be on the computer. Also, I'm going to leave a little story for [son with disability] onto his cassette or on the computer where he can read it, though we're not here, we're still thinking of him and things like that. [Son] wouldn't last.. I couldn't take [son with disability] to put him even next door cause he likes to be with his familiar things. He has his way. He has his books there he likes to read. and he has his music and stuff, you know. In a group home, they're only allowed a radio. He couldn't survive that.

Why is there such a discrepancy between what people recognize as a need and what they have done about responding to that need? Obviously, the answer is extremely complex. Despite the advanced age of the study participants and serious health problems for some, they believed that planning would come down the road. Many said they 'live one day at a time' and offered the view that living day-to-day was a challenge in itself so that not a lot of energy was left for seeking out options. They indicated that a balance was needed between worry and immediate need.

Well, I live one day at a time. Well, maybe one minute sometimes but one day at a time. I don't think about tomorrow because I can only live for today. I think that's what keeps me going because if I didn't, I'd be... I'd be sick myself worrying about, you know... and we know we have an awesome God that will look after us, so you know..

One father commented with 'tongue-in-cheek' that "I'm planning to live to be 100. I can continue to do this". Another parent hoped her son would 'go' before she did. Another said: "Well, I guess we're practicing avoidance pretty hard." The reality in all the provinces was that it required a great deal of effort by parents to search out what was available, become acquainted with eligibility processes, and get on 'waiting lists'. Even after all the effort was expended, there was no guarantee that what they really wanted would be in place nor that the services would continue to exist. And the

reality is that the level of care that parents provide may well be irreplaceable and this is painful for parents to address.

Parents had many decades of experience in seeing service philosophies change and programs/services come and go. They were realistic in accepting that even if they put things in place, there was no promise that the plans would hold in changing circumstances. This is a reality that everyone faces - there are no certainties and no promises of constancy. In the general population, while they certainly may be part of a consulting process, aging parents are seldom involved in actually planning the future for their adult offspring. They don't have the ultimate responsibility for the offspring's future quality of life, basic care and happiness. However, for the parents in this study and others who are caring for dependent adult sons/daughters, the need to plan is part of their reality and they find it an extremely isolating, discouraging task as there is little available to support the process: *"We won't even dare to think about it."*

It is clear that the centrality of the family in the care of the adult with disability can be a limitation because a comprehensive plan necessitates broader system involvement. Eligibility criteria, rigid rules particularly around financial issues, and lack of services were effective barriers to parents planning. While parents feel that it is mostly their role to plan, the execution and viability of the plans require systemic compliance. Thus, individual wishes and autonomy for future plans are framed to a large extent by the system. Perhaps this is the key understanding underlying the paradox. Some of the parents who had no formal plans in place expected the other adult children to take over the care, although they may or may not have discussed it with them. The researchers wondered if some of the other sons/daughters would be able to leave their jobs in larger centres to return to very rural areas.

Residential care was frequently mentioned as an element of future planning. For families where a move to alternative care had already occurred, the intent was that the son/daughter would stay there. For those where the son/daughter was living at home (76.5%), parents recognized that while they would want the son/daughter to be able to stay on in the home, that involved support staff in the absence of a full-time family member and issues about home maintenance, etc. In a few instances, it was expected that another sibling would move into the family home (ownership and transfer of home was part of the legal planning). For many in rural areas, there was little or no access to alternative living arrangements so that it was always a possibility that the son/daughter with disabilities may have to move from the community. In the rural areas, the sons/daughters were frequently very involved and supported in community life, thus a move would also cause a significant disruption to their social life.

Parents' willingness to take on the responsibility of providing for the comfort needs of their son/daughter can be thwarted on a societal level by restrictive policies. Policy barriers to planning were most evident in the financial arena. Most provinces have restrictive rules related to disability income supplements around the amount of income and reserve funds available to the son/daughter. In the fall of 2001, NF introduced welcome legislative and policy changes which permitted establishment of support trusts designated for sons/daughters with disabilities. The changes allow

these “*support trusts to be exempted when determining eligibility for social assistance and supportive services*” (The Western Star, Vol 51, No 248, Oct. 27/01). While families accept that basic needs will be provided for, they want to be able to offer the ‘little extras’ that contribute to quality of life: “...*like [daughter’s] welfare to me is... means more to me than money*”. Some parents have sought creative ways to provide for this.

When asked about future planning, some parents brought up the topic of wills. Only a few mentioned that they had wills in place - possibly linked to being stymied in so many areas even if they chose to plan. Some indicated that they were planning to prepare a will in the near future. Legal issues raised by the parents were related to guardianship and designating who would be responsible. In most cases, parents identified another son or daughter who would be the overseer; sometimes this was a verbal agreement buttressed by a sense of familial obligation.

Another common issue was designation of family home and assets. When a will was in place parents relegated assets to be used in the care of their disabled sons/daughters even if the assets were distributed to other family members.

Social planning is nebulous by its nature - it involves commitments of those who have affective ties with the family or person with disability. The highly successful organization Planned Lifetime Advocacy Network (PLAN), founded by Al Etmanski and Vicki Cammack in BC, is based on the development of social networks. This concept is the foundation for continuity in planning for social inclusion and meaningful activities. Parents make efforts to create this but recognize that they cannot ensure this happening - a distressing reality for them.

The majority of parents expect other siblings to take on the main responsibility for care of the disabled sibling. How that is operationalized differs greatly - for some, they mean actual physical care and shared living arrangements, for others, it means ensuring that the sibling’s needs are met and offering respite, affection and family traditions. Some parents indicated that they did not want their other sons or daughters to bear the full responsibilities, acknowledging that they had careers and families of their own. Often, responsibilities are divided among siblings (i.e. financial, care or social outings). In a few situations, a friend of the parent was prepared to help out although they may also be facing challenges in their own aging process. Friendship networks that can be involved were often cultivated by parents with the hope of offering continuity in support. Parents recognized, to varying degrees, that their role won’t be entirely replaced - there will be a fundamental change in the care provided.

Barriers to future planning exist within the parents themselves as well. Some acknowledge how hard it is to ‘let go’ and given the centrality of their role, this is not surprising. As well, there was a barrier in communications with professionals in that advice to ‘place’ a son/daughter often minimized the strong family bonds in the eyes’ of the parents. Placement is never an easy decision within families. It is imbued with layers of values, expectations and strong emotions. Parents did express that they would like to see some steps towards alternative living arrangements being taken while they were still around to monitor. This could be a source of ‘peace of mind’ for the parents as well if they observe

that their son/daughter was coping well. Other siblings recognize this benefit as well as expressed by the sister of a person with disability:

If we do this now, at the very least then Mom has you know, a hundred percent input and we can select a home that's going to be comfortable for them and their quality of life can improve for however much longer they're going to be living. For them and for us just to visit with them.

Only a few parents indicated that they had received encouragement from a professional about the need to put arrangements in place.

4.4.9 Inequities in Funding Arrangements

Across the provinces there were obvious inequities in available funding and often in policy interpretation. This emerged in dramatic ways where a member of a family had been deinstitutionalized and returned to the family home. Following him/her was sufficient funding to do an extensive renovation and provide continuous care. Other family members with disability were not entitled to these benefits and coped with minimal supportive care. One parent commented that she felt that parents who kept their sons/daughters at home were being 'penalized'. Another said of her constant fight: *"But you see that made me defensive, because I know.. because we kept our child, we were denied all those things [referring to services]."* In a few instances, there was both a biological son/daughter and a foster son/daughter residing in the family home. They were eligible for entirely different benefits, unrelated to the level of care needed. A father commented:

We've always been very conscious since [foster son] was 21 and he began his social assistance payments that the State is quite prepared to hand over significant amounts of money so that [foster son] can live in this house. They're not prepared to hand over anything like that to somebody who is our own son.

In addition to funding discrepancies there were also different services available in different areas within each province.

4.4.10 Challenges in Relationships

Despite the overwhelmingly positive elements that emerged in the parents' comments, there were a few families for whom the care was indeed a burden, resulting in negative or conflicted feelings around the relationships. Some parents felt that the excessive time required to provide care to the child with the disability meant that there was not enough time and attention spent with the other children and they felt some resentment from their offspring about that. The parents expressed guilt as well. Some felt a loss of opportunity in the activities they had to forego for their responsibilities. Some received little or no assistance from other family members in the care of the son/daughter: *"They never offer and I never asked."*

Some issues related to dependency emerged in that the parents acknowledged that they just couldn't let go: *"I hate to admit it but he's been my whole life"* or that they were so involved in the care that they knew that they may have not 'allowed' their sons/daughters to develop existing capacities to enable them to become more independent. A parent commented: *"I think we were catering to him a little bit too much. It was good for him to be more independent."* For many parents, there was always a fine balance between meeting very real needs and fostering autonomy, as limited as it may be.

Parents sometimes felt in conflict with the system as they were expected to provide all the care and yet they were limited in decision-making because of various policies. They wanted meaningful opportunities for their sons/daughters to participate in society and frequently expressed how they had to 'fight' for everything. A parent noted: *"I'm not really exaggerating that it is a continuous struggle and the changes come little step by little step. But if you stop fighting..."*. Because of the centrality of the parents in providing care, they found themselves in multiple roles of parent, caregiver, friend, advocate, health care provider, mediator, educator and social convener. These multiple roles are not expected ones for parents of adult children so they could find themselves out of sync with their peers. As well, they wished that their son/daughter had the opportunity to socialize with others outside the family.

The preceding discussion explored themes emerging from the interviews from an age-transition perspective. This perspective seeks to enhance our understanding of the realities in the lives of parents caring for their sons/daughters with lifelong disabilities and to illuminate areas of support needed for these families as they age. The following discussion (section 4.5) explores in greater depth the relationship between these parents and their adult sons/daughters to inform our understanding of how the parent-child relationship is affected by the presence of the disabilities. Together these perspectives provide a rich analysis to enhance our understanding of the daily experiences of these families.

4.5 Parent-Child Relationships

Descriptions of disruptive and cohesive daily practices were used as the starting points for the analysis of the underlying meanings inherent in the relationships between participating parents and their adult sons/daughters with disabilities. A model depicting the interdependencies between related ameliorating factors, relational processes, coping strategies, and outcomes emerged from the analysis (See Figure 1). From these understandings of the “perpetual parenting” ongoing in these relationships, a critique of ideologies of familialism and ageism as well as discourses of disability was developed.

The adult sons/daughters living with disabilities require varying levels of care. Some rely intensely on ongoing and regular physical care, stimulation and support by their parents while others are highly functional and are able to complete many tasks of self-care as well as assist their parents. These high-functioning individuals can often remain in the home unattended, they can take responsibility for food preparation and other household tasks and participate independently in social activities. For example, one parent noted:

Oh, she crochets and she's a great music buff and.. but she does dusting and she helps me change the bed, and.. you know. Now this morning before she went to work.. yesterday, say yesterday she emptied the dishwasher, put the garbage bag out, got the newspaper, put the milk in. This is before she goes to work.

Another parent referred specifically to her son's involvement in social activities:

His biggest activity is the church social. He worked with — Clubs, that's the children's program and he worked with the youngest group as an assistant to the teacher type of thing. And he enjoys that. the children think the world of him and he works well with those. Other than that I don't know. He loves to travel. He loves to eat out. He loves to eat period...

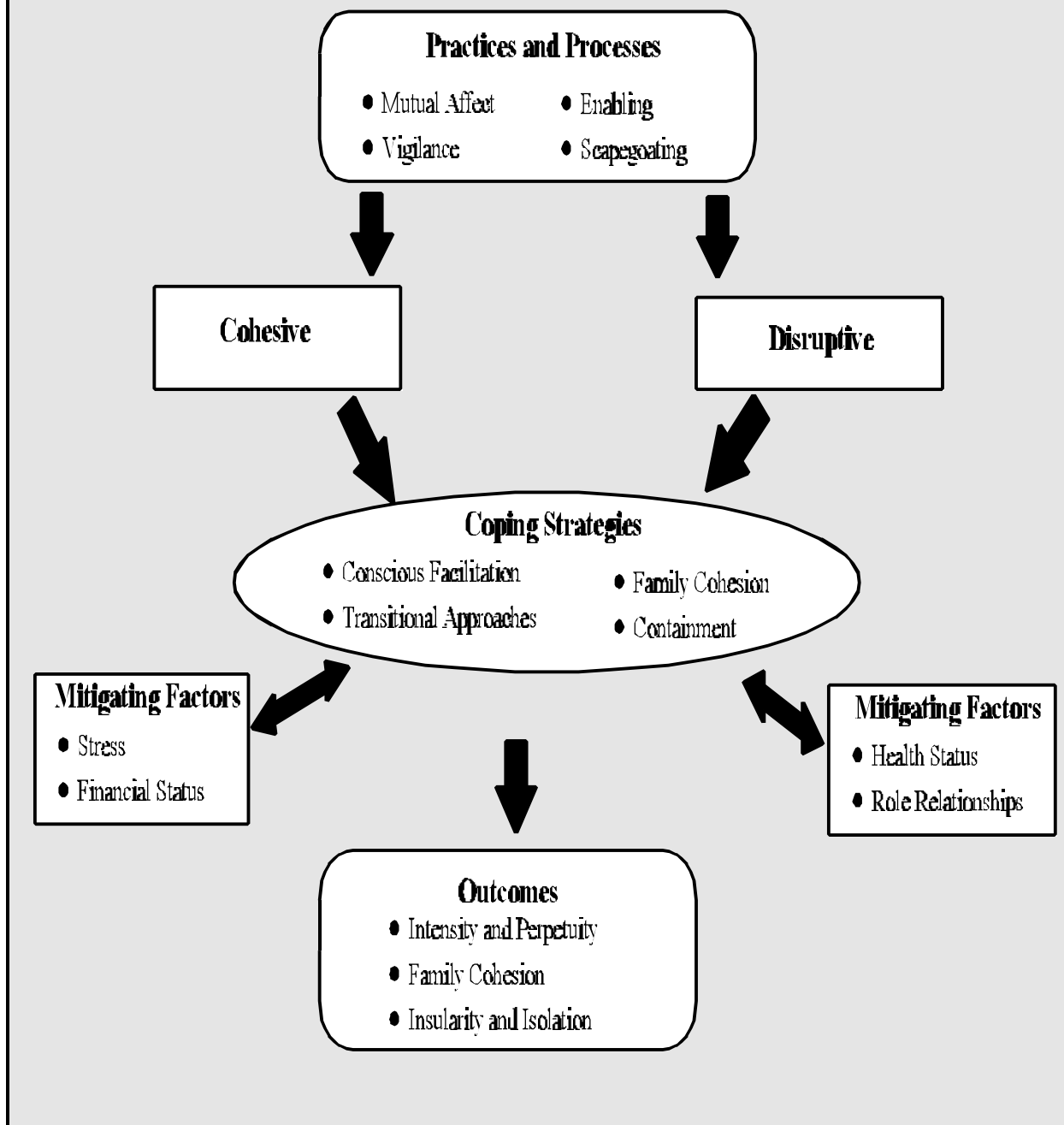
Others report:

... he's very neat in everything he does, when he gets up, he makes his bed and his clothes are all hung up neat and put away.

She washes the bathroom and kitchen .. and she peels potatoes, she washes dishes, peels vegetables, whatever.

Figure 1

Family Dynamics Model - Parents and Children



A range of tasks, activities and responsibilities are also assumed by the parents in these families. While some parents enjoy a wholly companionate relationship with their adult sons/daughters, others are, by necessity, focused on the day-to-day specifics of health care management and other task-oriented activities. For example, some parents participating in the study report that they take responsibility for the medical procedures that their children require such as catherizations, seizure management, administration of medications such as suppositories and hormonal therapies for menopausal daughters. Moreover, in some instances, parents feed, bathe and toilet those who live with more severe physical limitations and expedite morning routines by laying out clothes, preparing bagged lunches for those sons/daughters who leave the family home every day. Some of this daily work enacted by parents is visible in the following quotes:

You see now the medication makes him sleep all night but for years and years, he would go to bed after midnight and get up at 5:30, 6:00, so we had some fun days.

Well, I have to shave him and... I feed him and shave him and bath him and put him to bed, everything. Everything as far as personal care goes.

We've got to do everything for him, prepare his meals. He won't go to the washroom by himself, we've got to tell him to go.

Like she can be walking across the kitchen and fall down, like the muscles in her legs gives out and the muscle to her heart is weak and the muscles to her lungs is weak.

...like yesterday I couldn't move yesterday on account the girl had infection in her ears, she got bad ears and somebody had to treat her there but I ended up staying in the house all day because she was getting dizzy.. getting dizzy see and I had to stay in the house all day and watch her.

Well, with a lot of instructions and what have you, I can set her in there with the shower and she can shower herself, but you've got to make sure that she goes over everything and sometimes she'll take the soap and go up and down that arm 50 times, if you don't tell her.. you know. But all the time. She's like in a trance sometimes, you know, but then I'll say did you do your other arm? Oh. And she'll go right to the other one, and you know what I'm saying, so you got to give her supervision all the time”.

For all families, a clear picture of consistent and ongoing vigilance emerges from the words of participating parents. Watching, monitoring, and supervising permeate the daily lives of these parents. This vigilance is vital to the well-being of their adult children insofar as it enables healthy and productive living. Moreover, in some instances, parents shoulder complete and total responsibility for this work. One parent commented:

Well, she has been my life because for 38 years I've done everything. I've done everything. I learned her to walk. I went to physiotherapy with her and I learned the therapy and they

said she'd never walk, and I learned her to walk. I done the physio myself.

Enabling work is also revealed through some accounts of the ways in which parents mitigate the relationships between the adult child and the outside world. Parents accomplish this in a variety of ways particularly by seeking appropriate workshop and recreational activities that they believe will enhance the well-being of their children. One parent describes how her efforts to encourage her son to socialize have changed over time:

They have parties or something and he won't go to them. Of course, they.. you know, they're always at me and I said, look, I forced him to go until he was in his late '20's. I am not fighting with him anymore. He's 45 years old. If he doesn't want to go, I said there's perfectly normal people that don't want to go out and do that. He said, I see them all day long. I don't want to party with them.

The tangible practices and processes embodying vigilance and enabling constitute only one component of the daily and ongoing work of these parents. The daily lives of the parents are also permeated with emotional work. Maintaining family equilibrium in the face of the immensity of physical care is often dependent on the way in which the emotional needs of the adult sons/daughters are addressed. Many parents participating in this study name this aspect of their family life as periodically or perpetually overwhelming, but always salient and significant. The reality of this work is evident in the following quote:

No, but sometimes you're not feeling well and she'll be demanding... like I find in the mornings, I don't know if it's the medication or what it is, but she is so ugly and irritable, and she just gets in a repetition of "shut up".

The words of participating parents reveal a seemingly relentless experience of caregiving requiring ongoing vigilance. Vigilance characterizes both the emotional and physical work ongoing in these families. Furthermore, vigilance serves as an enabling force and results in an enhanced sense of family cohesion and mutual affect for some families. However, some parents interpret the vigilance of daily life as difficult and disruptive. This is illustrated in the following quotes:

I can't run up and down every time the.. you know, you give her her medicine and say now, go and brush your teeth now because you've had your medicine so she goes up, comes down. Did you brush your teeth? Yes. Three toothbrushes up there. So she didn't. I mean when I finally went up after she's gone, the toothbrush is still dry. So, this is what she'll do. And sometimes I'll check and sometimes they look probably okay, but when you check the toothbrushes, she hasn't brushed them.

Another parent described the difficulties experienced when parents are also undergoing age-related health transitions:

But now that I'm getting older, it's harder when they're both home, they were both home

for Christmas for two weeks and it's.. it keeps me busy I have to shave them, I wash their hair and I help them bath and it's.. it's much more work. You just sit down and they want something, get up and.. it's... I'm not 30 years old anymore, I'm 70. I'm going on 71 so..

A parent of a son with a psychiatric disorder has had particular experiences with the disruptiveness of vigilance:

Yeah, well he.. yes, and you know.. and I look back on that.. when you're right in it, you can't see the forest for the trees sort of thing, but.. or trees for the forest, or whatever it is, but anyway, when I look back on it now I know it's his frustration with his illness and.. now he told me one time later that when this happened, it was very scary because he had lost control. He had always been able to control his life before and he couldn't, and that was very scary. And so, you know, we were afraid to sleep at night. Well, I didn't put a lock on my door but my daughter did, but I would be sleepless and then have to get up in the morning and go.. And then I couldn't get him to go, you know, go out and do things or go to school or anything, so I'd go to work and he'd be sleeping all day. So then he was up all night while I was trying to sleep, you know

Interestingly, the same practices which are perceived by families as cohesive are construed negatively in other families. Family context and situational realities make the difference in this regard. As well, interpretations of experience can change over time. Factors such as stress, financial status, health status and role relationships mitigate and ease the experiences of the parents in some instances, but not all. The various interpretations of particular practices that emerged from this study afford an understanding of the complexities of the parent child relationships ongoing within and among families where aging parents are caring for adult sons/daughters with lifelong disabilities.

The parent-child bond within these families has developed within the context of the disability. The limitations and opportunities associated with particular disabilities serve as a back-drop for family interaction. Moreover, the often unrelenting responsibility for physical caregiving and emotional sustenance lends a particular intensity to these relationships. While some parents report that they receive many benefits in return, it cannot be denied that the parent-child bond, while mutually beneficial for some, is intricate and intense for all. This is visible in the following quote:

... he's not a perfect 37 year old, don't kid ourselves, but he's certainly.. he's very much of a gentlemen and what I like to hear people talk about how well he behaves, I don't mean I want to see a kid go around this all the time, but he's polite to people, he's polite to women, he's.. he does all the things you might expect a person to.. but he still has his fun, he still can pull your leg until it almost comes off you, as long as you get away with it. But he just handles himself I think quite well, and he's kind of a pleasure to be around. And a few little things, we can go out walking with the dog and almost every day when we're coming back he says, Father, I love you. And that's not said as a little child, I said, you know, as a meaningful sort of thing and I think people.. at least some disabilities can

communicate a sense of love, a sense of forgiveness that you and I would have a little trouble doing.

Insularity and isolation also emerge as important aspects of the parent-child relationships ongoing in these families. These realities result from a number of factors. For example, parents participating in this study indicate that their sons/daughters often encounter barriers which limit their participation in social support networks outside the family. In some instances, cognitive disabilities and personality traits that can be manifestations of specific disabilities can impede the development of non-family relationships. In addition, the dearth of social support services in many communities may mean that individuals with disabilities have no choice but to rely on immediate family for support. Compounding this is the professional discourse on disability which is constructed around ideologies that promote the separation of individuals living with disabilities into “special” schools, workshops, camps etc. All of this may mean that individuals living with disabilities can become dependent on the family system for support to the exclusion of all other potential or actual support systems. This may become a source of further stereotyping. The ideologically Eurocentric position on “dependence” characteristic of a liberal, democratic culture such as this tends to denigrate and devalue those deemed to be dependent. Some of the aging parents and their adult offspring with disabilities live with the manifestations of this stereotyping every day. Furthermore, a number report that they have found it important to negotiate these culturally prescribed and potentially delimiting messages and meanings within the family system and within their communities. One parent comments:

I find that it's.. and sometimes not even family. I think they mean well, but that was the one thing that I found.. I found that if you... like say for instance, oh, like my brothers and sisters are great, but I would never really sit down and.. what would I say? pour out my troubles, because I'd feel they'd think I'm looking for sympathy or, you know, expecting them to do something that.. whereas, now like for years I've belonged to the Community Living. Now, I don't now. But I found that, like if you.. say for instance you were a parent, I could say, oh, I had a bad day and, you know.. and they wouldn't.. they'd just talk back to me like.. I know what you're talking about and I feel like this and this, and you know, and you wouldn't feel like they think you're looking for help or sympathy or anything. They're just somebody to talk to. That's what I find that you can't... and then like even your own children, you don't like to say too much because that.. then they'd kind of half feel guilty, think they should be doing things and that, so.. but no, they've very good.

Another parent commenting on family members' reactions to her daughter notes:

Well, no matter what, they'll always throw [daughter's] name into it. No matter what. You think more of [daughter], or you do this for [daughter]... I say, yes, I do that for [daughter]. It was my choice to keep [daughter]. [Daughter] was born this way through no fault of her own or anybody else's, but she had... I took it on to look after her and I will.

Parents participating in this study also indicate that they can become isolated. The roles and responsibilities of perpetual parenting can preclude opportunities to develop and maintain bonds with others outside the family. Isolation can also result if parents choose to adopt an advocacy role. Parents who advocate on behalf of their sons/daughters with disabilities are sometimes perceived as “radicals”. In communities where this label carries negative meaning, isolation can result.

Essentially, the intensity, perpetuity, isolation and insularity characterizing the daily lives of participating parents results in a parent-child bond that is often the main focus of life for both the parent and the child. This becomes acutely evident as the parents age. As parents age, they sometimes find it more difficult to maintain responsibility for the active and ongoing care of their sons/daughters with disabilities. For example, some parents noted that as they age they find it increasingly difficult to keep up with the needs of their adult children. Exacerbating this change in their lives is the guilt that these realizations evoke. The impact of aging and parental responses to this are highlighted in the following quote:

I mean this was a dear little child, just as dear as the rest of our children, and at this moment twice as precious because you know, he had this giant handicap we had to overcome. And of course, we had no idea of what we were facing. I mean we couldn't see down the road that we would be in the very great stress we're under now because we're so old.

Through this study, the *work* ongoing in families where aging parents are caring for adult sons/daughters with disabilities is displayed. Bringing this daily labour into view is a corrective to the invisibility of actual work processes in previous studies of these families. Instead of producing accounts of the experiences of these families that fall away along a “line of fault” (Smith, 1987) separating what these parents and adult children know about their daily lives and what ideological forms of expression and prevailing professional practice paradigms claim to be knowable, this study has recovered and rendered visible the daily practices characterizing the daily lives of these families. It attempts to understand the meanings associated with these practices and the ways in which these practices embody ideologies of familialism, ageism and ableism.

Older parents caring for their disabled sons/daughters with lifelong disabilities are doing important work. At a time when most seniors are focused on their own age-related transitions, these parents continue to play major roles in the continuing care of their children even as their resources lessen. As this research demonstrates, present policies and practices do not always meet the parents’ needs. The following section presents parents’ perspectives of needed services.

4.6 What Parents Said they Need

During the interview, parents were asked for suggestions of specific supports from the formal system that would help them in their role as parental caregivers. There were no parameters given in terms of the type of support that could be available. In all circumstances, parents

responded thoughtfully and reasonably, looking only for minimal supports to sustain them and in some cases, not looking for any help at all. Their responses centered around choices and options in services for their sons/daughters. The common themes emerging from this discussion are:

Appropriate housing options. A major barrier to residential planning is simply the lack of options available, complicated by geographic disparities. Even if group homes were available, there were often waiting lists and they may not be the option of choice. Alternative arrangements such as small options, supervised apartments, surrogate families or independent living were even less available. Parents want options that reflect the preferences of their sons/daughters and themselves, congruent with values and lifestyle.

Funding to offer sufficient choices. In all provinces, disability funding is provided based on established eligibility criteria. However, the funding is limited and may only be used for prescribed purposes, with little flexibility to move funds from one area to another. This is not a minor issue. Choices are fundamental to autonomy and independence and income is one of the major factors in providing choices. Therefore, limitations in flexibility in funding can directly affect autonomy and independence. Lack of flexibility in funding allocations can also set up the dynamic of having a particular service in place because that is what the funding covers when it is actually another service that is needed. Again, choices are shaped by values and lifestyle and are individual by definition. One example is that some families can access funds for respite care but they are not able to pay a family member to provide that care, whereas if the funds could be used to do this it may actually support the family unit.

Transportation services. In each of the Atlantic provinces, transportation was a major issue. Depending on the size of the province, regional population density, and the distance between areas creating very remote communities, people were disadvantaged in their quest to access transportation. In areas where there was accessible transportation available, there were priorities for access with social activities frequently at the bottom of the list. Transportation is not a luxury - it is an essential component in enabling persons to engage in community life, maintain social ties, and access health services.

Social Activities. Parents wanted creative options for social activities for their sons/daughters that would offer opportunities to expand their social network. In terms of future planning, this is not an idle thought. In fact, it can be a vital stepping stone to providing an ongoing network of support. Most of the time the parents took their offspring to social events; however, they would like them to have outings with peers in addition to time with parents. As some parents indicated, they didn't have the energy anymore to keep up with their son/daughter, so the fact was that the son/daughter's world has also shrunk considerably. Linked to this is transportation, because even if there are events available, if the parent no longer drives at night (or at all), it is not possible to attend.

Opportunities to be involved in decisions. Listening to the voices of the parents was the underlying purpose of this study and the parents interviewed welcomed the opportunity to have their stories heard. They indicated that they wanted their voices to be heard at all levels, including making

decisions that affect them and their families directly. Despite the reality that these parents are the primary source of care, playing a significant role in the health and social services systems, they are rarely consulted on policy and program development. They would also like their sons/daughters to have a voice where possible. Parents have a great deal of expertise acquired over many years, evident in their visible advocacy role.

Respite. The need for respite care is an urgent one. Care demands are great and while parents have a lifetime of coping and managing quite well, they also need some time to recuperate and restore their energies. This again is not a luxury but a necessity in supporting the ongoing role of parents. Many families had some respite care but it was very limited. In some cases, the parents refused to accept the services offered for respite because a different ‘stranger’ would appear each time. They would like information on who would be offering care, not an unreasonable expectation as the parents are acutely aware that their son/daughter is very vulnerable. Services for respite need to be offered on the parents’ terms, in ways that are responsive to their needs with flexibility and choices. Respite care presents an excellent opportunity for adjusting to new settings and different caregivers. When there is a partnership with the families and providers offering services for respite, there is also the opportunity to begin transition planning.

Emergency support. A few of the parents interviewed had no other family members in the immediate area. For them, a sudden illness or accident (involving them) would present a major issue in the care of their sons/daughters. Parents need a back-up system which can respond in a crisis - preferably within the home setting so as to minimize anxiety and the disruption in routine for the son/daughter. The irony is that in many ways, because of the barriers to planning when parents try to put things in place, the system actually fosters crisis but is ill-prepared to respond to it.

Training/Work Opportunities for adults after school age. Generally, there are few opportunities for meaningful employment for adults with disabilities and where they exist, they may offer only a stipend in wages. For some parents, their sons’/daughters’ participation in the workshops was a major part of their social and community life. While the researchers are aware of the ongoing discussions about the role of the workshops, for the parents with whom we spoke, the experience provided the only available opportunity for their offspring to have a daily activity outside of the home. In many areas of the provinces, once the sons/daughters no longer qualified (age criterion) for public school there were simply no options. Some parents felt that their sons/daughters could benefit from life skills courses and they wanted activities that were appropriate to their sons’/daughter’s abilities and individual strengths. As well, training was needed to reflect the developmental delays and reflect the sons’/daughters’ realities.

“Navigation” - help with the system. Even for those who are familiar with the many layers of bureaucracy, navigating - or finding one’s way - through the complexities of the system can be a daunting task. This issue consistently surfaced in earlier work conducted by the NSCA as well (Langille, MacLellan & Berrigan, 1998; Langille-Ingram, MacLellan & Porter, 2000). Because the nature of the disability is such that the services cross many departments, parents find that they spend a great deal of time just trying to find out who to call - many times they just give up. They also find

themselves challenged when multiple assessments have to be completed and the information needs to be gathered and shared. Further, frequent reorganizations and renaming of services add complexity.

One of the primary goals of this research project, repeatedly endorsed by the parents in the interviews, was to identify and bring forth key issues facing older parents caring for sons/daughters with lifelong disabilities; parents wanted their voices heard and this information used to inform and guide policy decisions. To this end, parents, policy makers, civil servants and representatives from agencies/organizations supporting older parents caring for sons/daughters with lifelong disabilities were invited to public forums in their home province to hear and discuss the research findings. The following section discusses in detail the purpose and organization of the forums along with a summary of recommendations emerging from the discussions.

5. PROVINCIAL FORUMS

5.1 Forum Purpose and Rationale

Dissemination of the research findings to increase public awareness and inform and guide policy decisions affecting older parents caring for sons/daughters with lifelong disabilities was a primary goal of this project. Provincial forums were held in each of the four Atlantic provinces to present and discuss the research findings. The forums were organized in collaboration with the four provincial bodies in Atlantic Canada - the Disabled Persons Commission in Nova Scotia, the Premier's Council on the Status of Disabled Persons in New Brunswick, the Prince Edward Island Council of the Disabled Inc., and the Coalition of Persons with Disabilities of Newfoundland and Labrador. These organizations have specific interests in policy development and program planning and have observed the aging of their constituencies over the years. They co-sponsored the public forums for decision-makers, program planners, service providers and families. The objectives for the public forums were to:

- Provide a vehicle for the dissemination for the research findings;
- Validate of the research findings;
- Facilitate the opportunity to collect individual and collective recommendations on the dissemination of the research findings (who the target audience of the research findings should be, the type of information, the format and the methods to disseminate); and,
- Provide an opportunity for networking and the fostering of linkages by participants at the forums.

5.2 Forum Organization and Structure

Over 250 invitations to the forums were mailed/faxed or e-mailed to all parents in the four Atlantic provinces who had been interviewed for the project and the agencies/organizations who had facilitated the original contact with the families as well as other key agencies/organizations/government departments and political leaders. In addition, the co-sponsoring agencies informed their 'community' about the forum through newsletters, e-mail distribution lists and personal contacts. The forums were free-of-charge, but for logistical reasons a request was made for participants to respond to project staff if they were attending. The locations chosen for the forums were Corner Brook, Newfoundland; Fredericton, New Brunswick; Charlottetown, Prince Edward Island; and Halifax, Nova Scotia.

The forums were organized as half-day sessions with three principal components: (1) a presentation of the research findings by the co-principal investigators, in a user-friendly format to accommodate the diverse backgrounds and interests of the participants; (2) round table discussions by forum participants of the findings with the objective that they reflect on how the new information from the study could be moved into action; and (3) feedback from the round table discussions. Work sheets directed round table discussions to key questions (see section 5.4). The worksheets were collected,

and the results compiled.

5.3 Attendance

Forum participants included older parents with disabled sons/daughters (some were accompanied by family members and friends); and representatives from the civil service, and private and volunteer sectors involved with senior parents and the disabled. Table 5.3.1 reflects the diversity of sectors represented at the forums in each of the four Atlantic provinces. Actual attendance was higher but completion of the attendance forms was voluntary and some individuals chose not to complete them. Based on responses, elected officials in each of the four provinces were invited but did not attend any of the sessions.

Table 5.3.1 Participants at Four Atlantic Provincial Forums, by sector, 2001

| Sector Represented | Newfoundland | New Brunswick | Prince Edward Island | Nova Scotia |
|-----------------------------|--------------|---------------|----------------------|-------------|
| Parents & family members | 1 | 13 | 8 | 12 |
| Private agencies - FP | - | - | 1 | 2 |
| Volunteer organizations | 5 | 15 | 10 | 12 |
| Not-for-profit organization | 3 | 1 | 5 | 9 |
| Government - | | | | |
| - municipal/regional | 2 | 5 | 37 | 8 |
| - provincial | 5 | 10 | | 32 |
| - federal | - | - | | 1 |
| Elected representatives | - | - | - | - |
| Students/faculty | 9 | - | - | 5 |
| Total | 25 | 44 | 34 | 81 |

5.4 Discussion Arising from the Forum Roundtable

Each forum began with a presentation by the principal researchers highlighting the key themes arising from the research findings. After the presentation, forum participants divided into smaller groups to discuss strategies for further dissemination of the research findings. The following questions were addressed:

- What types of information are needed? For whom? What is the best way to present the information?
- What will make change happen? What are a) the barriers and the b) the enablers? How can the parents voices be heard?

Three recurring themes echoed throughout the forums: the need for advocates to take issues to government and foster political will; the dearth of information on services for both providers and families; and, for policy to reflect older parents' needs. These themes were embedded in the discussions arising from the forum questions.

5.4.1 What types of information are needed? For whom? What is the best way to present the information?

The forum participants endorsed the need for the project findings to be accessible to families, community groups and organizations, service providers and health care professionals, and policy makers and political leaders. However, it was evident at all forums that participants used the report findings as a spring board to discuss key issues at a much broader level. Participants acknowledged content and presentation style should be tailored to reflected the differing needs of the various stakeholders.

Families/parents/siblings. There was unanimous agreement at the four provincial forums that all parents of disabled sons/daughters should have access to the project findings. Furthermore, siblings need to aware as they are often involved with present care or in future plans. Therefore, information regarding care and resources would assist siblings in aiding their parents with present care and future planning as well as their own involvement with care. Participants felt that a critical need for families was gaining information on how to access services. The services identified included: financial and formal social support including respite, housing options, advocate/guardianship, workshop/employment options for persons with disabilities, emergency care, how to form support groups, transition information. It was suggested that this information could be accessed by families through a one point entry system (an updated central directory where services and resources for all communities are recorded). Suggestions on ways to improve access to information included: a hotline number, information packages, public service announcements, seminars, newsletters and brochures. It was felt that sharing of family experiences and best practices would help to empower families to make decisions based on the context of their lives.

Community Groups. Forum participants identified the following community groups that would benefit from access to the research findings: advocacy groups, professional health educators, educators in the school system, community organizations such as volunteer organizations and support groups. The community needs to be informed of the reality of families caring with sons/

daughters with disabilities and availability and access to resources for these families. It was felt that parents sharing their experiences with the community would increase understanding from others and therefore encourage voluntarism and advocacy on behalf of this population. Dissemination of research findings could also be dispersed through the media via reporting research highlights, public information sessions and through presentations to community groups such as the Legions, Lion's and Rotary Clubs.

Service Providers and Health Care Professionals. The service providers identified as potential recipients of the project findings included: formal caregivers and respite workers; physicians, social workers, health professionals, lawyers, and Councils of the Disabled. Participants felt that service providers need ongoing information and training regarding current treatment and care for persons with lifelong disabilities and their families. Persons working with these families need to be informed of current resources available to assist families as they are in intimate contact with families and can provide the link to other resources such as respite and workshops for the disabled. Information for service providers could be accessed through training sessions and workshops, public service announcements, formal reports, parent presentations, newsletters. It was suggested an information hot line be established to assist service providers with current information and resources for families.

Policy Makers, Bureaucrats and Government Leaders. Forum participants felt that it was very important that policy makers, bureaucrats and government leaders be provided with the project findings. Their list included politicians at the federal, provincial and municipal levels, the Senate and the Council of Maritime Premiers. Their rationale was that policy makers need information to aid their understanding of the everyday realities of families caring for adult sons/daughters with lifelong disabilities and how current policy impacts these families. They need information on the gaps between services and family needs in order to address policy changes in meaningful ways for these families. This includes financial realities of care, funding inequities within the current system, prioritization of needs by the families, education on age transitions for parents and persons with lifelong disabilities, demographic statistics related to this population, and present resources available to these families. Access to this information could be achieved through presentations, meetings with parent representatives, statistics and reports.

5.4.2 What will make change happen? What are the barriers and enablers?

There was a general sense at all four Atlantic forums that a crisis will make change happen for individual situations, but will not "fix" the big picture; and, there was an underlying recognition and acceptance that change does not happen as quickly as forum participants might want or expect.

Forum participants identified barriers that inhibit the dispersement of information and affect the services and resources available to help families. These included: lack of funding, inequities in funding, current policies, lack of political will, lack of trust in current system, social attitudes and lack of knowledge of the realities of families caring for sons and daughters with lifelong disabilities, lack of flexibility in system, and fragmented social services system. It was generally felt that a lack of visibility and awareness of the key issues relevant to older parents with adult sons/daughters with

disabilities were significant barriers to political change. For example, even if adequate resources were available, attitudes and the status quo can act as barriers to change. Participants felt that government is afraid to individualize programs (to provide necessary flexibility) because they fear people would ask for the “moon”. However, they observed the report findings provided evidence to the contrary and therefore endorsed this information needs to be disseminated to policy makers.

Adding complexity, as pointed out during the New Brunswick forum, it is now considered politically incorrect to assign labels to individuals with lifelong disabilities making it more difficult to quantify its prevalence. A participant suggested, “Numbers are needed because politicians only respond to numbers”. It was also suggested that “parents need to get labels back - naming the issue without marginalizing”.

Forum participants identified many factors that can initiate change. In Newfoundland, participants reported that: “Demographic change may push it [change] or else it will become a crisis”. In Prince Edward Island, participants pointed to the power of, “A few committed people from both the community and the system working together” and lauded parents’ organizations who have “made things happen in PEI”. In New Brunswick the importance of collaboration was also endorsed along with the recommendation to continue to lobby for change:

“Remember we are not in it alone - there are more families, government agencies and leaders and organizations - and we need to get everyone moving in the same direction at the same time to move forward and make change”.

In Nova Scotia, participants observed the environment might be ripe for change as provincial money is currently being allotted to communities and regions, commenting that, “We can only shop if we have money”.

Many suggestions of “change initiators” were gleaned from the forum participants. In summary:

- **Education.** Education opens minds, leads to innovative thinking and a caring community. Information on age related transitions associated with disability, for both those with disabilities and their parents, should be integrate into the curricula of health care professionals. Currently there is a dearth of information on disabilities in medical education. There needs to be opportunities for parents and people with disabilities to educate professionals (teachers, service providers), the community, and other families. Public education can remove fear/stigma so families are more comfortable accessing the system. It is also important to inform the justice system with emergency information (protocol) on who to access when dealing with intervention issues with this community. Wise use of the media can facilitate change. Creative strategies for educating the public to the realities of families caring for those with disabilities can inform the political will of the people and bring about appropriate and effective change.

- **Knowledge.** It was noted that most government policies/programs have mission statements that speak to family values; these need to be highlighted. Increase awareness of issues and make system ‘user friendly’ so people have dignity left after attempting to access funding.
- **Empower families.** It was suggested that families need to be encouraged to form support and advocacy groups. There needs to be more opportunities for parents to share information and concerns. Information sharing empowers people.
- **Advocacy.** Advocacy includes lobbying government and providing a “voice” for parents. Individuals were encouraged to make personal contact with politicians and educate MLAs, starting with one case at a time. Another suggestion was to initiate private members’ bills to bring about change. It was felt it was important to have a voice at government tables, particularly as new frameworks are being developed in long term care, as is currently happening in New Brunswick. The need to expand adult services and for the province to move away from a focus on abuse and protection to one of prevention was also noted. It was suggested senior parents need to mobilize and connect with associations and advocacy groups, such as the Seniors Federation and Active Community Living.
- **Coordination and Collaboration.** There needs to be collaborative efforts among NGOs, government and families. Increased communication and collaboration among seniors organizations and disability groups would bridge the aging and disability sectors. This would improve organization and support planning. Coordination of policies and programs among government departments (health, community services, education, etc.) would improve access to services and service delivery. Increased involvement in coalitions (eg. Community Action Coalition) and strong leadership would help present a united front for change at local and provincial levels of government.
- **Research.** Participants agreed research is needed to identify both the need for and the cost of services and to link this information with creative and effective solutions. Qualitative studies would examine the affects of caring for a person with a disability over a life time (longitudinal studies) and would also provide an opportunity to include the “voice” of the adult sons/daughters. Change can also arise from proof of cost effectiveness. There is the need to look at the cost of programs and the benefits to the disabled and their families but it is important to understand that costs and benefits should not just be measured in terms of dollars. Quality of life, dignity, family cohesion, etc. should also be included. Participants also suggested that researchers should “*flip the coin and ask the care providers (home support workers, respite workers) to get the other side*”.

5.4.3 How can parents voices be heard?

When the forum participants were asked how parents’ voices could be heard the same themes were reiterated:

- Change attitudes and *“treat people as individuals. We have no idea how to help parents’ voices be heard because historically they haven’t been heard; but have been surveyed to death!”*
- Go public. For example, increase political pressure and educate the public using cable, video, newspaper articles, CBC, National Film Board, perhaps a ‘Chicken Soup’ book for parents stories. Use Open line shows, forums/workshops and conferences.
- Provide resources and establish connections. For example, Seniors Federation and Active Community Living, support groups, coalitions and advocacy groups, and provide parents with resources so that they can attend sessions. Act collectively. There is “strength in numbers”; many voices make a stronger message; build networks and advocacy. Families need to know they are not alone.
- Advocate and lobby. It is important to move the personal story to the political level. Call politicians! Be assertive. Appeal decisions made by government. Parents have to get together for advocacy purposes and to be supported in ways to reach their government officials and others to bring about change. Parents also need to learn how to find easy access - and to navigate the system. Be involved and use public education in the schools.

Forum participants endorsed the need for the recommendations emerging from this study to be delivered to both political leaders and service providers. The following section highlights recommendations emerging from this project.

6. IMPLICATIONS AND RECOMMENDATIONS

Analysis of the results from the *Older Parents Caring for Adult Sons/Daughters with Lifelong Disabilities* study yields clear implications for both policy and practice. Policy implications apply to either municipal, provincial or federal levels of government, depending on the jurisdictional responsibility. Practice implications could apply to a diverse range of professionals and service providers in areas of health care, residential services, social services and education. Ten recommendations emerge from the implications for both policy and practice.

The messages conveyed in this section were evident from various sources of information: literature review, Public Forums in four Atlantic provinces, interviews with fifty-six families in four Atlantic provinces, and feedback from collaborators and community agencies.

6.1 Policy

6.1.1 Family Lens

A fundamental issue which emerges from the study relates to the need to examine the assumptions (comprising inherent beliefs and values) underlying the policies affecting aging families caring for adult offspring with lifelong disabilities. Policies affecting these families are typically constructed from a disability or rehabilitative perspective. However, the findings of this study support the application of a **family lens** when developing and implementing relevant policies and programs. The use of a family lens situates the family as the unit of care and facilitates the provision of services in a manner that sustains and supports these families in their many roles.

The application of a family lens acknowledges families as central sources of social support to those with lifelong needs. Moreover, the use of a family lens permits the assessment of unmet needs in a manner that recognizes that care is not a uni-dimensional function but rather a process, changing over time, and affected to varying degrees by multiple factors. Thus, this lens transcends the prevailing assumption that ‘one policy fits all’. This opens the door to a system where policies are constructed to meet individual need, a development which represents a departure from the current system whereby families must somehow fit within the parameters and contours of particular policies. A family lens changes the perspective for every aspect of service, including eligibility criteria and allocation of limited resources.

Recommendation 1 (a): We recommend that all levels of government use a family lens to frame public policy.

Recommendation 1 (b): We recommend that publicly funded services be expected to use a family lens in delivery of services.

6.1.2 Flexibility

Existing public policies are often inflexible which is then reflected in the range of publicly funded services that are offered. This inflexibility acts as a barrier, preventing easy access to existing services. This barrier often results in parents failing to use an existing service because of a lack of fit, or in being denied a needed service because of restrictive eligibility criteria. Policies which apply to aging families caring for adult sons/daughters need to ensure flexibility in design, interpretation and implementation. Policies need to ensure that services are offered on the user's terms, rather than the system's terms. For example, services that result in respite for the parental caregiver need to reflect the family's needs in timing and location.

Recommendation 2: We recommend that flexibility be incorporated as a key value underlying policy development, interpretation and implementation.

6.1.3 Funding

Currently, access to funding support is based on a social welfare model and as such, carries with it a stigma for some people. Further, there are significant inequities between what the system will pay to support persons in residential care and what is offered to families who are providing the care at home. Costs incurred in providing care at home can be significant and can increase for aging families as they strive to accommodate changing needs. For example, transportation may emerge as a new cost if the parent(s) is/are no longer able to drive or there may be renovations necessary within a home to install a ground floor bathroom or ramps. As well, restrictions in policies related to either income earned or given, which define the parameters of eligibility for disability income, can actually inhibit future planning. For example, parents do not want to decrease their son/daughter's disability income by leaving small amounts of money for comfort needs. (The province of Newfoundland has recently introduced progressive legislative and policy changes in this area.) In addition, parents need more flexibility so as to use funds in a way which best supports their sons/daughters' well-being. Many other studies have also pointed to the need for a review of existing funding policies.

Recommendation 3: We recommend that funding policies be reviewed with the intent of increasing flexibility and minimizing inequities.

6.1.4 Preparedness

According to the estimates derived from the quantitative component of the study, there are approximately 20,000 Canadians 65+ who are providing care to their dependent offspring. Currently, policies and programs have not kept pace with the changing needs of these families as they age. As two-thirds of the study sample were in their 70's and 80's, it is likely that within the next ten years there will be considerable demands on the system. Coupled with the reality that many parents do not have future plans in place for a variety of reasons, it is reasonable to expect that there will be a surge

in demand for residential, financial and social services. Following this age cohort is another which constitutes an estimated group of 40,000 baby boomers (between ages of 45-64) who are caring for adult offspring. Given that the system appears to be overtaxed at this point, as evidenced by reports of waiting lists or unavailable services, it is critical to consider the system's preparedness in the next two decades. Without this, it is likely that the system will be reactive, most often to crisis, rather than proactive, in responding to changing needs of the population of aging parents caring for aging sons/daughters with lifelong disabilities.

Recommendation 4: We recommend that policies be reviewed with a view to determine their applicability and flexibility to respond to changing family needs as both caregiving parents and adults with lifelong disabilities age.

6.2 Practice

6.2.1 Range of Services

Implications for practice arise from consideration of the range and types of services that are available to aging families and designed to support them in their work or which present alternatives when parents are no longer able to continue being the sole provider of care. Services need to be sensitive to changing needs over the life course and offer contingency components. This study provided an entry point to understanding these needs and contingencies in that it used the everyday experiences of participating parents as the starting points for the research. In so doing, it offered a voice to the parents, a voice which is absent from public discourse on aging and disability. This points to the need for continued and ongoing opportunities for parents caring for adult sons/daughters with disabilities to tell their stories. Educational/support groups can offer a supportive environment which opens up a space for the absent voices and absent experiences of these parents. In addition, individual family-focussed counselling services need to be available to those who may benefit from therapeutic intervention.

Recommendation 5: We recommend that service providers initiate family-focussed services that support the aging family unit and respond to their changing needs.

6.2.2 Cross-training between aging and disability sectors

As the population of parents and sons/daughters with lifelong disabilities ages, new challenges arise with respect to the relationship between the aging and disability sectors and their roles in serving this population. It is clear that professionals and service providers who have been prepared in the traditional philosophies of either the aging or disability sectors need additional training if they are to effectively understand and serve the changing needs of their clientele. There are specific situations where service providers and receivers would benefit from cross-training. For example, parents in some areas voiced a concern when adults with lifelong disabilities are placed in nursing homes

because of a lack of other alternatives. As the training and programming in these sites focus on meeting the needs of an elderly, frail population who are the majority of residents, the needs of a few residents (sometimes only one) with lifelong disabilities may be inadequately met. Cross-training is also important to encourage the effective use of community resources. For example, some pilot projects have been successful in integrating those with lifelong disability into existing community programs for seniors (with considerable support and education for everyone involved).

Recommendation 6: We recommend that curricula for service providers who serve this population in the aging and disability sectors be reviewed to ensure course content includes material relevant to aging with a lifelong disability.

6.2.3 Future Planning

The tasks of future planning, including legal, financial, residential and social spheres, are critical in preparing for the transition from parental care to other providers of care. Few parents have plans in place and fewer still report receipt of encouragement from professionals and service providers to do this. Planning, while centred on family values, beliefs and resources, is significantly affected by systemic factors which have the potential to mitigate the effectiveness of the plan. For most families who receive public funding support, planning cannot occur without some input from the system. Assistance with planning tasks needs to be integrated into the professional role of service providers and be seen as part of case management. Linked to this is the availability of options for parents and offspring to 'try' as a step in determining suitability.

Recommendation 7: We recommend that assistance in future planning be appropriately funded as a recognized service.

6.2.4 Later life options

As parents age, their capacity to provide care to adult sons/daughters often decreases and their own needs for support may increase with age-related health or social issues. At the same time, the needs of their aging offspring may increase. As well, existing activities such as work placements may be no longer suitable for some of the aging adults with lifelong disabilities and there are few, if any, opportunities for them to take on new social roles and activities in retirement. Not only does this present new challenges for families but it also positions residential service providers in such a way that they will find it important to re-evaluate current services. There are also implications for funders in terms of either reallocating resources or making new resources available.

Recommendation 8: We recommend that retirement options for older persons with lifelong disabilities be an area for program development.

6.2.5 Health care

Parents frequently spoke of the lack of knowledge, among health care providers, relevant to aging

of those with lifelong disabilities. This not only causes unnecessary distress and discomfort for individuals and families, but often, treatable conditions can be overlooked, which, had they been diagnosed early might mean prevention (or amelioration) of serious outcomes of ill health. The lack of information was not confined to unusual age-related conditions but was also evident in everyday health scenarios, the most commonly mentioned being menopause and dental care. With growing numbers of persons with lifelong disabilities living into old age and the likelihood of living in non-institutional settings, it is important that health care providers receive additional education about the needs of this population.

Recommendation 9: We recommend that curricula for health care providers include both expected and potential health issues for persons aging with lifelong disability.

6.2.6 Navigation

Although there may be existing services in the community for families, these services may be underutilised, or ineffectively used, because the families either do not know about them or they do not know how to access them. Barriers include family dynamics, literacy, fears related to disclosure of financial information, difficulty in finding the right department or person to call, voice mail, and complex rules and eligibility criteria. Consistently, the need for assistance with ‘navigation’ - finding one’s way through the maze of the system - emerged as a key theme.

Recommendation 10: We recommend that a navigator position be created within each province to support families seeking information and services from the formal system.

6.3 Summary of Recommendations

- Recommendation 1 (a):** All levels of government use a family lens to frame public policy.
- Recommendation 1 (b):** Publicly funded services be expected to use a family lens in delivery of services.
- Recommendation 2:** Flexibility be incorporated as a key value underlying policy development, interpretation and implementation.
- Recommendation 3:** Funding polices be reviewed with the intent of increasing flexibility and minimizing inequities.
- Recommendation 4:** Policies be reviewed with a view to determine their applicability and flexibility to respond to changing family needs as both caregiving parents and adults with lifelong disabilities age.
- Recommendation 5:** Service providers initiate family-focussed services that support the aging family unit and respond to their changing needs.
- Recommendation 6:** Curricula for service providers who serve this population in the aging and disability sectors be reviewed to ensure course content includes material relevant to aging with a lifelong disability.
- Recommendation 7:** Assistance in future planning be appropriately funded as a recognized service.
- Recommendation 8:** Retirement options for older persons with lifelong disabilities be an area for program development.
- Recommendation 9:** Curricula for health care providers include both expected and potential health issues for persons aging with lifelong disability.
- Recommendation 10:** A navigator position be created within each province to support families seeking information and services from the formal system.

7. DISSEMINATION OF INFORMATION

7.1 Provincial Forums

An important component of the *Older Parents with Adult Sons/Daughters with Disabilities: Age-Related Transitions* project was to share findings with families, service providers, program planners and decision makers. The Co-Principal Investigators presented the findings from the interviews at public forums in each of the four Atlantic Provinces. This provided an opportunity for discussion and input into policy recommendations. The Newfoundland forum was held in Corner Brook at the Glyn Mill Inn on Friday October 12, 2001. The New Brunswick forum was held in Fredericton at the Monsignor Boyd Family Centre on Thursday October 25, 2001. The Prince Edward Island forum was held in Charlottetown at the Quality Inn in the Hill, Friday October 26, 2001. The Nova Scotia forum was held Monday, October 29, 2001 at the Penthouse, Mount Saint Vincent Motherhouse. For forum attendance see Table 5.3.1

7.2 Presentations

Contributions of Adult Sons/Daughters with Lifelong Disabilities to Their Aging Caregiving Parents. The 17th Congress of the International Association on Gerontology. World Congress of Gerontology, Vancouver, BC. 2001.

Older Parents Caring for Adult Sons/Daughters with Lifelong Disabilities: Age-Related Transitions. A Preliminary Report. Graduate Research Seminar in Department of Family Studies and Gerontology, Mount Saint Vincent University, Halifax, Nova Scotia. 2001.

Older Parents' Experiences and Perspectives of the Actual and Future Living Arrangements of Their Adult Children with Disabilities. 29th Annual Scientific and Educational Meeting, Canadian Association on Gerontology: Edmonton, AB. 2000.

Older Parents Caring for Disabled Adult Sons/Daughters. The 17th Congress of the International Association on Gerontology. World Congress of Gerontology, Vancouver, BC. 2001.

Older Parents Caring for Adult Sons/Daughters with Disabilities: Integrating Their Voices. The Sixth Annual Qualitative Health Research Conference, Banff, Alberta. 2000.

Prevalence and Nature of Caregiving Among Older Persons in Nova Scotia. The 17th Congress of the International Association on Gerontology. World Congress of Gerontology, Vancouver, BC. 2001.

Through the Parents' Eyes: Experiences of Caring for Adult Sons/Daughters with Lifelong Disabilities. Graduate Research Seminar, Department of Family Studies and Gerontology, Mount Saint Vincent University, Halifax, Nova Scotia. 2000.

Workshops/Lectures:

What Families Value in Support Services. Regional Residential Services Annual General Meeting. Fall, 2001.

Age-Related Transitions and Service Needs of Older Parents Caring for Adult Sons/Daughters with Lifelong Disability. National Meeting of Provincial Disability Advisory Councils, Halifax, NS. 2001.

Growing Older with Lifelong Disabilities. Focus 2000 - Educational Conference for Regional Residential Services. 2000.

7.3 Media Interviews

The media contacts to date are as follows:

NFLD:

Interview on CBC Morning Show, Oct. 12/01.

Pre-workshop Article interview (Oct. 12/01).

Article in Western Star, Oct 17/01.

PEI:

Interviews with CBC English and French radio, Oct. 26/01

CBC TV

CBC Mainstreet

CFCY Radio

Print articles Charlottetown Guardian, Journal Pioneer (Summerside), Oct.27/01

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APPENDICES

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APPENDIX 1

Consent Form



**Older Parents Caring for Adult Sons/Daughters with Disabilities:
Age-Related Transitions**

PARTICIPANT CONSENT FORM

INTRODUCTION:

You are invited to participate in an interview as part of a research project intended to study the changes that happen in caregiving relationships as parents and adult sons/daughters with disabilities age. The research also intends to identify the types of support that are needed by these families as they grow older. The project is funded by NHRDP and is being conducted in four Atlantic provinces. The researchers are working in collaboration with the Nova Scotia Disabled Persons Commission, the Premier's Council on the Status of Disabled Persons, the Coalition of Persons with Disabilities - Newfoundland and Labrador, and the PEI Council of the Disabled Inc. to ensure that the findings are shared with the people and groups who design policy and programs.

Agreeing to be interviewed is voluntary. You may stop the interview at any time or refuse to answer any questions which may be particularly uncomfortable for you. Your participation will not affect any other programs with you may be involved and it is not related to any services, including income programs, which you may receive.

PURPOSE OF RESEARCH:

The purpose of this research is to enhance our understanding of how the care that older parents provide for adult sons/daughters who have disabilities changes as both groups age and to identify the types of services that would be most helpful to these families as they prepare for future transitions.

RESEARCH PARTICIPANTS:

The researchers wish to interview parents who are 65 years of age or older who are caring for an adult son/daughter with a developmental disability.

PROCEDURES INVOLVED IN THE INTERVIEW:

An interviewer will come to your home for the interview or meet you in another location which may be more convenient for you. The interview will be 1.5 to 2 hours in length and there may be follow up contact for clarification. The interviews will be taped and later transcribed by a project assistant. The tapes and transcripts will be stored in a secure setting. Only the researchers associated with the project will have access to them.

CONFIDENTIALITY

You will not be identified by name in any reports or publications nor will your name or the name of any other participants be shared with any group or agency.

QUESTIONS

If you have any questions about the research or would like to obtain more information about the interview, please contact the researchers:

Dr. Deborah Norris - Co-Principal Investigator
Department of Human Ecology
Mount Saint Vincent University
Halifax, NS B3M 2J6
Tel. 902 457-6376

Marlene MacLellan - Co-Principal Investigator
Nova Scotia Centre on Aging
Mount Saint Vincent University
Halifax, NS B3M 2J6
Tel. 902 457-6546

If you would like to speak with someone who is not directly involved with the research you may contact:

Dr. Cynthia Mathieson
Director of Research
Mount Saint Vincent University
Halifax, NS B3M 2J6

CONSENT

I have read the information provided on this form and understand the purpose of the research. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction.

Name of Participant

Signature

Date

APPENDIX 2

Interview Guide

Interview Guide

Opening Questions

Hello

How are you?

We would like to thank you for participating in our study. We truly appreciate your willingness to take the time to share with us some of your experiences about your experiences and your son/daughter's experiences. *(elaborate)*.

Before we start, we would like you to know that we will protect the confidentiality of the information that you share with us. We will also send you a copy of the interview transcript so that you can verify the accuracy of the interview. As well, please remember that you can stop the interview or choose not to answer specific questions at any time during the interview. If you find the interview too tiring, please let us know, we will take a break.

Adult Son/Daughter

We would like to start by asking you some questions about your son/daughter.

What is his/her name?

How old is s/he?

What kind of disabilities does s/he have?

Workshops/Programs/Day Centres

Let's speak about your son/daughter's life now.

Does s/he go to a day program/sheltered workshop during the week?

What kind of workshop/day program is it?

Whose idea was it?

How often does s/he go there?

Does s/he like going there? Why? Why not?

Do you think it is important for him/her to go to a workshop/day program? Why? Why not?

Was it easy to find a workshop/day program for him/her?

How does s/he go there?

Do you have any transportation concerns?

Do you have any suggestions to improve your son/daughter's experiences with his/her workshop/day program?

Ensure that following topics are covered: transportation to and from workshop/daycare (including cost of transportation if appropriate), relationships between caregiver/s and staff, staff and adult son/daughter, adult son/daughter and other clients, learning experiences.

Adult Sons/Daughters Social Activities

Can you tell us about your son/daughter's friends?
What does s/he do together with his/her friends?
How often do they see each other?
Do you think it's good for him/her to have friends? Why? Why not?
How does his/her having friends affect your own life?
Does your son/daughter go to any special social activities like dancing or bowling?
How often?
How does that affect your own life?
Who drives them there?

Adult Sons/Daughters Independence

Can you tell us some of the things that your son/daughter can do for himself/herself?
Does s/he help you?
Can you give us some examples
Can your son/daughter be left alone for a few hours at a time?
Some parents have told us that their son/daughter could have been more independent if they had not always done everything for them. Do you think that's also true for you?
Can you give us some examples
Why did you do that?
Are there any areas where you tried to teach your son/daughter to be more independent?
Why? Why not?
How difficult was it?

Ensure that following areas are covered: personal grooming, household activities, functional ability, transportation, decision making/executive functioning, orientation to time, place, social/work activities.

Relationships with Siblings

Do you have other children?
Are they close to your son/daughter?
Do they do things together?
Are there tensions at times between your adult son/daughter and his/her siblings?
Around any specific issues?

Living arrangements

Does your son/daughter live with you?

Why? Why not?

For parent/s whose children live with them:

What is it that you particularly enjoy about having your son/daughter with you?

Is it hard to have your son/daughter live with you at times?

When? Why? What happens?

Has s/he always lived with you?

Why? Why not?

How did that affect your life/lives?

Did your son/daughter always live with you?

If not, what did you particularly like or dislike about the previous living arrangements?

For parents whose children do not live at home:

Where does your son/daughter live?

If appropriate: Is it run by a volunteer organization or the province?

Is s/he happy there?

When did s/he move there?

Why did you make that decision?

Was it a hard decision to make?

Did you involve other people in your decision?

Did they help?

Why? Why not?

What did you do once you made that decision?

How did you carry out that decision?

Did your life change since your son/daughter moved away?

How? Can you give us some examples?

Are you happy with the changes?

Do you have any concerns about your son/daughter's living arrangements?

How could they be addressed?

Did your son/daughter lived in other types of residence?

What did you particularly like or dislike about these other living arrangements?

Try and explore relationships between staff and parents, staff and adult son/daughter, adult son/daughter and other clients, quality of in-house services.

For all the carers:

Other parents have told us that their spouse did not always agree with their decision (to keep their adult son/daughter at home or to move them to a different environment), did that happen to you too?

What happened?

Do you think that this disagreement may have affected your relationship with your spouse?

Was it a short-term effect or a long-term effect?

Did it affect your relationship or your spouse's relationship with your son/daughter?
Does your spouse now agree with you?
Why? Why not?

Caregivers' Lives

Let's talk about you now and your life/lives.
Are you the main caregiver/s of your son/daughter?

For how long have you been taking care of your son/daughter?
Has this always been so?
Are you taking care of anybody else?
Could you tell us your age/ages?

For parents whose children live at home:

Can you describe a typical day for you?
What do you do?
What does your son/daughter do during the day?
What is a good day like for you and your son/daughter?
How often do they happen?
Do you do family things with your son/daughter?
What do you think are the most important things you should do for your son/daughter?
Do you do these things?
Why? Why not?
Can you tell us about some of the things that you particularly enjoy about caregiving? Why do you enjoy these things?
Can you tell us about some of the things that you may not like as much when taking care of your son/daughter?
Why do you not enjoy these things?
Do you still do these things? Why?
Some parents, particularly mothers, told us that they would be heartbroken if their adult son/daughter did not live with them. Would you feel the same way? Why? Why not?
How would you describe your relationship with your son/daughter? *Ask for clarifications if necessary.*
What kind of things does your son/daughter do for you?

For parents whose children do not live at home:

Can you tell us about some of the things that you do for your son/daughter?
How often do you see each other? Talk to each other?
Do you do family things with your son/daughter?
What do you think are the most important things you should do for your son/daughter?

Do you do these things?

Why? Why not?

Do you enjoy taking care of your son/daughter? What is it that you particularly enjoy? Why?

Are there parts of caregiving that you don't enjoy?

Which ones? Why?

Do you still do them? Why?

How would you describe your relationship with your son/daughter? *Ask for clarifications if necessary.*

Carers' Social Life

What do you do during your spare time, if you have any?

Do you go out sometimes? By yourself/yourselves?

What arrangements if any?

Do you do things just for yourself/yourselves?

What sorts of things?

Crises

Can you remember the last time you had a crisis that involved you son/daughter?

What happened? What did you do?

Did you have any help? Any support? Safety nets?

Does that happen often?

Do you experience other types of crises at times?

Can you tell us about them?

How do you cope?

Do you have any support? Help?

Do you have other children? Where do they live? Do they have any problems?

Other issues

Some parents told us that they have a very special relationship with their son/daughter with disabilities, that this relationship was unlike their relationships with their other children, is this also true for you?

In what ways is your relationship with your son/daughter with disabilities different from your relationships with your other children?

Can you give us examples?

Why do you think that is?

How do you feel about it?

Does your caregiving have any impact on your financial resources?

Can you give us some examples?

How does that affect your life/lives?

Could that be changed?

How?

Relatives= and Friends= Support

Could we talk about the people you help you or who have helped you.

If appropriate: Do your other children help you?

How?

How does that affect your daily life/lives?

Do you have relatives who help you?

What do they do?

Do you have friends or neighbours who help you?

What do they do?

How does that affect your life/lives?

Aging

Of the adult son/daughter:

What changes are your son/daughter experiencing, as they get older?

What about health changes?

Emotional changes?

Social changes?

Financial changes?

Of the caregiver(s):

What has aging meant for you?

What changes are you experiencing?

What about health changes?

Emotional changes?

Social changes?

Financial changes?

Are there things that you did for your son/daughter that you cannot or don't do any more? What things? Why? Who does them?

Are there things that you did with your son/daughter that you don't do anymore?

Why? How do you feel about that?

Are there things that your adult son/daughter did for you that s/he can no longer do?

What things?

Have these changes affected your relationship with your son/daughter?

How? How do you feel about that?

Have these changes affected you in other ways? (*Ensure that all changes are covered*)

How do you cope?

Does anybody help you do some of the things that you cannot do?

Did you receive any additional help as a result of these changes?
What kinds of help would you like to receive?

The community environment

School:

At what age did your son/daughter go to school?
What was it like for him/her?
What was it like for you?

Physicians:

Tell us about your experiences with doctors?
What are they like?
How do you feel about them?
Was it always like that?
Can you remember a particularly good experience with a doctor?
Can you remember a particularly bad experience with a doctor?
How did that make you feel?
Can you think of changes that might lead to improve relationships with or services from doctors?

APPENDIX 3

List of Nodes and Definitions

Q.S.R. NUD*IST Tree and Node Definitions

- (1) **Base Data.** Definition: Demographic Facts
 - (1 1) Base Data/Participant(s). Definition: Parent or parents of disabled adult child
 - (1 1 1) Base Data/Participant (s) /Sibling participant. Definition: Sibling present and actively involved and contributing to the interview
 - (1 1 2) Base Data/Participant(s)/ Parent. Definition: Gender of parent
 - (1 1 2 1) Base Data/Participant(s)/Parent Father. Definition: Father present at interview
 - (1 1 2 2) Base Data/Participant(s)/Parent/Mother. Definition: Mother present at interview
 - (1 1 3) Base Data/Participant(s)/Marital Status. Definition: Present marital status of parent(s)
 - (1 1 3 1) Base Data/Participant(s)/Marital Status/Married. Definition: Participant(s) is married or common-law
 - (1 1 3 2) Base Data/Participant(s)/Marital Status/Single. Definition: No present partner
 - (1 1 3 2 1) Base Data/Participant(s)/Marital Status/Single/Widowed. Definition: Spouse deceased
 - (1 1 3 2 2) Base Data/Participant(s)/Marital Status/Single/Never married. Definition: Single parent
 - (1 1 3 2 3) Base Data/Participant(s)/Marital Status/Single/Separated or divorced. Definition: Separated or divorced
 - (1 1 4) Base Data/Participant(s)/Employment History. Definition: Current Employment Status
 - (1 1 4 1) Base Data/Participant(s)/Employment History/Employed. Definition: Currently working outside the home
 - (1 1 4 2) Base Data/Participant(s)/Employment History/At home. Definition: Currently at home, no paid employment
 - (1 1 4 2 1) Base Data/Participant(s)/Employment History/At home/Homemaker. Definition: Has always worked at home as a homemaker
 - (1 1 4 2 2) Base Data/Participant(s)/Employment History/At home/Retired. Definition: Retired from paid workforce
 - (1 1 5) Base Data/Participant(s)/Socioeconomic status. Definition: Socioeconomic status (SES)
 - (1 1 5 1) Base Data/Participant(s)/Socioeconomic status/upper SES. Definition: Evidence that family - mother father - have professional jobs, university education, high income, etc.
 - (1 1 5 2) Base Data/Participant(s)/Socioeconomic status/lower SES. Definition: Indications that family has very low income, little formal education, etc.
 - (1 1 5 3) Base Data/Participant(s)/Socioeconomic status/middle SES. Definition: Indications from interview that family is "middle class"
 - (1 1 6) Base Data/Participant(s)/Other Children in family. Definition: Other children besides disabled child
 - (1 1 7) Base Data/Participant(s)/Other caregiver participant. Definition: A participant in the interview who is not a parent or sibling but is a significant caregiver (i.e. sibling's spouse)
- (1 2) Base Data/Child. Definition: Adult child with disability
 - (1 2 1) Base Data/Child/Gender. Definition: Sex of child with disability
 - (1 2 1 1) Base Data/Child/Gender/son. Definition: Son with disability
 - (1 2 1 2) Base Data/Child/Gender/Daughter. Definition: Daughter with disability
 - (1 2 3) Base Data/Child/Living arrangements. Definition: Where the disabled son/daughter live
 - (1 2 3 1) Base Data/Child/Living arrangements/Home. Definition: Disabled son/daughter live at home
 - (1 2 3 2) Base Data/Child/Living arrangements/Sibling's home. Definition: Disabled son/daughter live with a sibling
 - (1 2 3 3) Base Data/Child/Living arrangements/Other living arrangements. Definition: Other living arrangements for disabled son/daughter - not at home or with siblings
 - (1 2 3 3 1) Base Data/Child/Living arrangements/Other living arrangements/Relative's home
Definition: Disabled son/daughter lives with relatives other than siblings
 - (1 2 3 3 2) Base Data/Child/Living arrangements/Other living arrangements/unique arrangement
Definition: Living arrangements for disabled child that does not include other relatives home, group home or institution.

- (1 2 3 3 3) Base Data/Child/Living arrangements/Other living arrangements/Group home. Definition: Disabled son/daughter lives in a group home
- (1 2 3 3 4) Base Data/Child/Living arrangements/Other living arrangements/Institution. Definition: Disabled son/daughter lives in an institution
- (1 2 4) Base Data/Child/Disability. Definition: The type of disability noted for the adult son/daughter
- (1 2 4 1) Base Data/Child/Disability/developmental disability. Definition: Son/daughter has a developmental disability
- (1 2 4 2) Base Data/Child/Disability/Psychiatric disability. Definition: Son/daughter has a psychiatric disability
- (1 2 4 3) Base Data/Child/Disability/accident. Definition: accident causing brain damage and/or physical disabilities

- (1 3) Base Data/Age. Definition: Age of parent and/or child
- (1 3 1) Base Data/Age/20-29. Definition: 20-29 years of age
- (1 3 2) Base Data/Age/30-39. Definition: 30-39 years of age
- (1 3 3) Base Data/Age/40-49. Definition: 40-49 years of age
- (1 3 4) Base Data/Age/50-59. Definition: 50-59 years of age
- (1 3 5) Base Data/Age/60-69. Definition: 60-69 years of age
- (1 3 6) Base Data/Age/70-79. Definition: 70-79 years of age
- (1 3 7) Base Data/Age/80-89. Definition: 80-89 years of age
- (1 3 8) Base Data/Age/90+. Definition: 90 years of age and over

- (1 4) Base Data/Location. Definition: Location of interview
- (1 4 1) Base Data/Location/Urban. Definition: Family interviewed lives in an urban area (city or large town)
- (1 4 2) Base Data/Location/Semi-rural. Definition: Family interviewed lives in a semi-rural area (small town or village)
- (1 4 3) Base Data/Location/Rural. Definition: Family interviewed live in a rural area (some distance from stores, other houses)
- (1 4 4) Base Data/Location/semi-urban (town). Definition: Large towns with access to support services such as a hospital.
- (1 4 5) Base Data/Location/remote. Definition: Rural, remote with respect to services or almost isolated housing.

- (1 5) Base Data/Province. Definition: Province where parent participant resides.
- (1 5 1) Base Data/Province/Newfoundland. Definition: Newfoundland
- (1 5 2) Base Data/Province/New Brunswick. Definition: New Brunswick
- (1 5 3) Base Data/Province/Nova Scotia. Definition: Nova Scotia
- (1 5 4) Base Data/Province/Prince Edward Island. Definition: PEI

(1 6) Base Data/culture specific. Definition: Culturally specific traditions and practices.

- (1 7) Base Data/Household Composition. Definition: Other family members living within the household.
- (1 7 1) Base Data/Household Composition/other children in household. Definition: Other children living in the household other than the disabled child(ren)
- (1 7 2) Base Data/Household Composition/Other close relatives. Definition: Other close relatives of person being interviewed, i.e .parents, aunts, uncles, sister, brother, cousins,
- (1 7 3) Base Data/Household Composition/Not relatives. Definition: Other people living in the household who are not relatives

(2) Reciprocity. Definition: The give and take between family members; how they help each other.-has been re-coded to sub categories.

- (2 1) Reciprocity/Intangible benefits. Definition: The inter-psyche benefits to self and to the family associated with caring for the adult child. Copy of node (16) .
- (2 2) Reciprocity/learning from experiences. Definition: Copy of node (F 5) .Reflections on how family and the

- system learned from the experiences with adult son/daughter with disabilities.
- (2 3) Reciprocity/Child's contribution to community. Definition: Benefits that accrue to community as a result of action by the adult child with disabilities as perceived by parent/sibling.
 - (2 4) Reciprocity/Tangible family acts. Definition: Physical give and take between family members and the adult disabled child which bring benefits to the parents/family

(3) Disruptive Behavior. Definition: Any behaviour from the disabled child that is considered by parents to be distressing or disruptive to themselves or others.

(4) Transitions. Definition: Transitions include milestones or changes that initiate new needs

- (4 1) Transitions/health. Definition: Changes in health of parents or sons/daughters
- (4 1 1) Transitions/health/parent. Definition: Changes in parent's health that affected their caregiving
- (4 1 2) Transitions/health/child. Definition: Changes in son/daughter's health that created new needs
- (4 1 5) Transitions/health/aging. Definition: Copy of node (4 5) . ADD Definition printed out Sept 10 - age related transitions
- (4 2) Transitions/marital status. Definition: Change from married to single through widowhood or divorce
- (4 3) Transitions/work. Definition: Retirement of parents or of child; transition from school to work for the child; transition from home to workplace for mother.
- (4 4) Transitions/regular activities. Definition: Changes in regular activities that mean different routines
- (4 6) Transitions/Acknowledgement of Disability. Definition: The experiences associated with the acknowledgement of the disability.
- (4 7) Transitions/an experience. Definition: An event or experience that has caused the family to change behaviors
- (4 8) Transitions/housing. Definition: Changes in housing for the parents or for the adult child, i.e. moving out of the family home to a nursing home or group home. Also temporary moves
- (4 9) Transitions/sibling death. Definition: The impact of the death of the adult child's sibling.
- (4 10) Transitions/Parent death. Definition: Transition as a result of death of Participant's (older parent) parent.

(5) Social Support. Definition: Social support includes formal and informal supports.

- (5 1) Social Support/Formal. Definition: Paid services provided by agencies or individuals
- (5 1 1) Social Support/Formal/health & social support. Definition: Emotional and physical support from medical and auxiliary health professionals such as rehabilitation & social workers This also includes LACK of
- (5 1 2) Social Support/Formal/School-education. Definition: Support through the formal education system
- (5 1 3) Social Support/Formal/workshops, special programs. Definition: Support through programming and paid staff-includes workshops, special programming, camps, social activities
- (5 1 4) Social Support/Formal/volunteer organizations. Definition: Support and services offered through volunteer agencies
- (5 1 5) Social Support/Formal/Politicians. Definition: Bureaucrats advocating for family needs, policy changes, etc.
- (5 1 6) Social Support/Formal/Gov Income support. Definition: Income support programs offered by any level of gov.
- (5 1 7) Social Support/Formal/Residential care givers. Definition: Paid staff in group homes, institutions, etc. where the disabled are living.
- (5 1 8) Social Support/Formal/Private Paid help. Definition: Parents have hired help from their own funds to help with care of child or to enable them to maintain and stay in their home.
- (5 2) Social Support/Informal. Definition: Unpaid services offered by family, friends or volunteers
- (5 2 1) Social Support/Informal/other relationships. Definition: Copy of node (7 2) and its subtree. Relationships outside the family, Includes paid informal babysitting, and informal business practices

(6) Family Dynamics. Definition: Interactions between and among family members

- (6 1) Family Dynamics/Siblings. Definition: Interactions with siblings/ disabled child
- (6 2) Family Dynamics/Parent-child. Definition: Interactions between parent and child (this includes both

- disabled and other children)
- (6 3) Family Dynamics/Extended family. Definition: Interactions with extended family members
 - (6 4) Family Dynamics/family activities. Definition: Activities family members do together
 - (6 5) Family Dynamics/other caregiving responsibilities. Definition: Caregiving being provided to other family members or others
 - (6 6) Family Dynamics/Gender Relations. Definition: The ways in which ongoing caregiving is informed by assumptions that appear to differ by gender.
- (7) Coping Strategies.** Definition: Practical, emotional and spiritual strategies that enable parents to cope with their roles and responsibilities.
- (7 1) Coping Strategies/faith. Definition: Adherence to formal religion or expression of spirituality, belief in a higher being
 - (7 2) Coping Strategies/Professional Help. Definition: Seek professional counselling to help deal with present problems.
 - (7 3) Coping Strategies/perspective. Definition: Parent's general viewpoint
 - (7 4) Coping Strategies/Personal attributes. Definition: Personal characteristics that help shape people's responses to their circumstances
 - (7 5) Coping Strategies/hobbies or activities. Definition: Any interest identified by the parent as something that they do and gives them pleasure
 - (7 6) Coping Strategies/care coping strategy. Definition: Copy of node (F 1) . Strategies families used to manage the care of their son or daughter. This can include emotional and physical care strategies.
- (8) Future Plans.** Definition: Residential, financial, legal and social plans for the care of the adult disabled child when the parents are no longer able.
- (9) Needs for service.** Definition: Needs expressed by the parents for services that would assist them.
- (10) Present concerns.** Definition: Issues of immediate concern to parents
- (10 1) Present concerns/Parent's health. Definition: Changing or existing health issues of the parent
 - (10 2) Present concerns/Child's health. Definition: Changing or existing health concerns of child
 - (10 3) Present concerns/safety. Definition: Parental concern for disabled child safety in the home or in the community
 - (10 4) Present concerns/future caregiving. Definition: Parents express concern in interview about caregiving if they should become sick, infirmed or die.
- (11) Income.** Definition: Issues related to income of son/daughter with disability
- (12) Functional Abilities.** Definition: Mental and physical abilities/disabilities of parent or child.
- (12 1) Functional Abilities/related to parent. Definition: Health conditions and status described by the parents
 - (12 2) Functional Abilities/related to child. Definition: Health conditions and status of the child as described by the parents
- (13) Perceptions.** Definition: Beliefs that people hold, may reflect their values or knowledge
- (13 1) Perceptions/what others may think. Definition: Perceptions that others may hold as described by the parents
 - (13 2) Perceptions/Personal feelings & understandings. Definition: Feelings and understandings or perceptions described by the parents

- (14) **Culture.** Definition: Cultural ways of knowing\being embedded in the intersecting experiences of aging, family and disability.
- (15) **Everyday family Practices.** Definition: The daily practices characterizing the everyday worlds of parents and adult children.
- (15 1) Everyday family Practices/child's daily activities. Definition: Ability of child to handle money, do chores, etc. as perceived by parent
- (17) **Special challenges.** Definition: Challenges specific to a family's situation for example frequent relocation
- (18) **Interview.** Definition: All entire documents coded to this category for analysis.

FREE NODES

- (F 1) //Free Nodes/**Social isolation of parent.** Definition: Parent feels socially/physically isolated from family or community.
- (F 2) //Free Nodes/**concern over quality of child's life.** Definition: Comments made that reflect concern about the quality of the disabled child's life - past, present and/or future
- (F 3) //Free Nodes/**wishes.** Definition: Comments made by parents that reflect the wishes of the parents
- (F 4) //Free Nodes/**methodological issues.** Definition: Methodological issues re the process: ethical concerns, giving voice, therapeutic value of participating, member checking and software.
- (F 5) //Free Nodes/**Advice for other families.** Definition: Parents sharing what they have learned they may be of benefit to other parents sharing similar experiences.
- (F 6) //Free Nodes/**cost of care.** Definition: References to emotional or other costs of caring for the individual- could include travel, visiting other family members, sense of not doing enough
- (F 7) //Free Nodes/**romantic relationship of child.** Definition: Romantic interest or relationship of son/daughter with disability
- (F 8) //Free Nodes/**Social action for change.** Definition: Activities that benefit disabled persons in general: such as lobbying government, increasing public awareness, leadership/fund raising
- (F 8 1) //Free Nodes/**Social action for change/advocacy for child**
Definition: Parent indicates that they were advocates for their child - this is more than seeking and getting services, perhaps seen as fighting for the right
- (F 8 2) //Free Nodes/**Social action for change/advocate for other families**
Definition: Parents indicates that they have advocated for other families
- (F 9) //Free Nodes/**Transportation.** Definition: issues and concerns related to getting around
- (F 10) //Free Nodes/**Quotable Quotes.** Definition: Quotes which may be used in report.
- (F 11) //Free Nodes/**Dependency.** Definition: Material, practical or emotional connection between parent and child which functions to sustain family dynamics (positive/negative)
- (F 12) //Free Nodes/**Integration-mainstreaming.** Definition: Attitudes and experiences with

integration-mainstreaming in school and workplace